A LONGITUDINAL EXPLORATION OF THE EXPERIENCE OF FRONTO-TEMPORAL DEMENTIA IN INTERGENERATIONAL FAMILIES

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Abstract

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A longitudinal exploration of the experience of fronto-temporal dementia in intergenerational families

Key words**:**

Family relations, frontotemporal dementia, longitudinal, qualitative research, coping

Background:

Dementia presents challenges for whole families requiring on-going adaptation. Family relationships provide important benefits, thus understanding the impact of dementia for families is critical to facilitating their wellbeing. Behavioural variant Frontotemporal Dementia (bvFTD) brings specific challenges for relationships, however little is understood about how these are experienced or how families adjust.

Aims:

This research sought to develop an in-depth understanding of the inter-generational family experience of bvFTD over time.

Method:

Using a qualitative design, nineteen people were interviewed from seven families, including people living with bvFTD. Interviews occurred over three time points. Narrative analysis and grounded theory were used to understand how relationships are affected and the psycho-social coping processes involved in adjustment over time.

Results:

Four themes emerged;

- Cohesive and connected --- distant and disconnected
- Challenges to we/ I

- Assimilating, adjusting and reconstructing --- resisting, denying, being stuck
- A changing we / I --- an entrenched we / I

Results illustrate the influence of pre-existing relationships on family experiences of bvFTD. Challenges to family relationships occurred, including changes in mutuality and increased responsibility. Levels of awareness and understanding, influenced by factors such as proximity impacted upon individual and family adjustment. Assimilating these changes was critical to developing strategies for managing the impact on the relationship and adapting to ‘a changing we’. For closest family members including partners, grief and loss were experienced resulting in the need for a parallel adaptation to a changing ‘I’. Acceptance and adaptation was critical to supporting the wellbeing of the person with bvFTD.

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There are a number of people that I wish to thank for their contribution to this endeavour. I particularly wish to extend my gratitude and appreciation to the seven families who have taken part in my PhD research. Without their courage, openness and ongoing willingness to contribute their perspectives and experiences I would not have been able to realise this goal. I am also very appreciative of the support offered by Jayne as her insights have been incredibly valuable over these six years.

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Finally, I wish to thank The Florence Nightingale Foundation, The General Nursing Council for England and Wales Trust and The Atkinson Morley and Amandus Club Neuroscience, whose funding supported me for three years of my PhD.

Dedication

This thesis is dedicated to Andrew, Gemma and my family whom I love more than it's possible to express. It is also dedicated to all of the people living with dementia and their families who I have had the honour to work with throughout my career. Your strength and courage is an inspiration to me.

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Chapter 1: Introduction

1.1 Personal statement

I came to this research study as a result of a long journey, having worked with people living with dementia and their families since qualifying as a Mental Health Nurse in 1982. In the mid 1980's I was introduced to working therapeutically with families by Alison Roper Hall, a Consultant Clinical Psychologist with expertise in family therapy. This was an important learning opportunity for me and influenced my thinking and my practice going forward. For example, I undertook a small research study exploring how families understood and coped with dementia for my MA dissertation in 1995. This research emphasised for me how important it was to view dementia in the context of family relationships, recognising that all family members including the person with dementia actively influenced how dementia was experienced.

During this time, opportunities for learning and developing my practice encompassed working therapeutically with families living with dementia including those families experiencing young onset dementia. Working with people living with young onset dementia and their families brought the need for a relational context to practice into sharp focus for me because family members such as children, young people and parents were highly visible and had needs that were not always met by services. Furthermore, people living with less common forms of dementia such as frontotemporal dementia (FTD) appeared to experience particular challenges to relationships. Their experience appeared markedly different from families living with Alzheimer's disease, because FTD impacted directly on relationships due to its effect on social and emotional functioning. The challenges these families faced represented a steep learning curve for me as I tried to understand how to help them, particularly in the context of an absence of relevant research to guide and support interventions.

While research into FTD gained momentum between 2000 and 2010, this rarely translated to a focus on interventions which supported people living with FTD and their families. Furthermore, the perspectives of people living

with bvFTD remained unheard in this research, despite a broader acknowledgement in research and practice of the need to achieve this (Wilkinson 2002). Thus my efforts to develop my understanding and support families including the person with bvFTD were often challenged and there were times when it felt I could offer little more than a listening ear. Over time I realised that this was a significant gap that needed to be addressed. Thus in 2010, I began this research study to explore the family experience of living with bvFTD.

My experience as a practitioner, researcher and educator has influenced my reasons for undertaking this study and has affected the way that I have carried it out. Additionally it influences what I hope this study will achieve. This research has inevitably influenced my perceptions of myself as a partner, mother, step-mother and grandmother within my own family, with all the joys and challenges this brings and therefore influenced the way in which I have interpreted the data and developed the stories being told. In this thesis, I provide an account of a qualitative longitudinal study with seven families who live with behavioural variant frontotemporal dementia (bvFTD). Furthermore I consider the practice implications of their experience.

1.2 Background and context to this research

Dementia is identified as one of the most serious health challenges facing the world at this time (Prince et al. 2015). Current evidence suggests that there are 46.8 million people worldwide who live with dementia. Furthermore, it is it is suggested that there are around 850,000 people in the UK who experience Dementia Syndrome (Prince et al. 2014). These authors also identify that of those 850,000, 42,325 people are living with young onset dementia in the UK, although Lambert et al. (2014), suggest that accurate estimations of the prevalence of young onset dementia are complex and difficult to achieve. Prevalence rates are expected to continue to rise and by 2025, it is estimated that over 1 million people in the UK will live with dementia (Prince et al. 2015). In this context, it is widely acknowledged that research and practice development need to occur in order to provide effective, person and family centred interventions and care for people living with dementia and their families. Various authors have suggested that research considering the

experience and needs of people living with dementia and family members and the interventions that might be required has developed in three phases (Ablitt et al. 2009; Whitlach 2001; Woods 2001). These phases (focus on caregivers, focus on people with dementia and a relational focus) are summarised below to give context to the place of the current study.

The first phase involved research into family caregiving. It has been acknowledged that family members provide the majority of care and support needed by people living with dementia (Prince et al. 2015; Luengo-Fernandez et al. 2010). Furthermore it is suggested that one in three of us will provide care to a family member with dementia at some point in our lives (Dowrick and Southern 2014). As well as providing much needed support and care, families are thought to facilitate wellbeing and maintain self-esteem and identity of people living with dementia (Livingston et al. 2008). Research suggests that caregiving for a family member with dementia is associated with satisfactions including the opportunity to reciprocate and having a close relationship with the person with dementia (de Labra et al. 2015; Andrén and Elmståhl 2005; Lloyd et al. 2014). However, evidence also attests to the negative outcomes that occur, including poor physical and mental health (Gallagher-Thompson et al. 2012).

Furthermore, despite increasing recognition of the challenges of caring in the context of dementia, some have suggested that there has been a failure to meet the needs of family caregivers (Knapp and Prince 2007). In recent years, government guidance and policy has sought to address this. Indeed the most recent Prime Minister's challenge 2020 (Department of Health 2014) identified that services should work towards greater personalisation of care and support for the person with dementia, their carer and their family.

Alongside this focus on the needs of family caregivers, various authors have increasingly stressed the need to involve and include people living with dementia in research and practice in order to better understand the support and interventions needed (Kitwood 1997; Woods 2001; Whitlach 2001). These and other authors have emphasised that people living with

dementia are active agents in addressing the impact of dementia on their lives. Furthermore, Woods (2001) suggested that the interrelationship between people with dementia and their family caregivers cannot be ignored, as they have a reciprocal influence on each other's wellbeing.

Consequently, over the last decade, a second phase of research has emerged concerning the experience of dementia from the perspective of the person with the diagnosis, highlighting their needs and demonstrating their ability to actively contribute to research and practice development (Ablitt et al. 2009).

For example, in a recent systematic review and synthesis, Wolverson et al. (2016: 697) established that people have the ability to 'live well' with dementia which involves retaining strengths and positive experiences in spite of their diagnosis. They also suggest that dementia care and research needs to explore ways in which these strengths and positive opportunities can be sustained to help the person to live as well as possible. Furthermore, given the acknowledged link between the wellbeing of the person with dementia and their family caregivers, it is feasible that active strategies to improve the wellbeing of the person with dementia are likely to have an additional effect of improving the wellbeing of family caregivers (Ablitt et al. 2009).

Given this increasing body of research evidence, it is perhaps unsurprising that the third and most recent phase of research has involved an exploration of the impact of dementia upon relationships (Ablitt et al. 2009; Quinn et al. 2009). The focus on relationships between the person with dementia and their family caregiver has established that factors such as shared coping strategies and the quality of the prior relationship impact upon the experience of dementia (Ablitt et al. 2009; Hellström et al. 2007a; Keady and Nolan 2003). However, the majority of studies in this area have concentrated upon the relationship between couples (c.f. Hellström et al. 2007a; Wawrziczny et al. 2014; Davies 2011) and have rarely considered other family relationships. Furthermore, the perspective of the person with dementia has often been missing from such research.

Nevertheless, this research confirms that a range of family members are affected by dementia. These include young people with a parent with dementia and adult daughters and sons (Camden et al. 2011; McDonnell and Ryan 2011; McDonnell and Ryan 2014; Ward-Griffin et al. 2007; Piercy 2007; Sechrist et al. 2012; Svanberg et al. 2011; Denny et al. 2012; Gelman and Greer 2011). Furthermore, this research suggests that all family members, including the person with dementia, seek to actively address the impact of dementia on their lives (Hellström et al. 2007a; Allen et al. 2009; Roach et al. 2014b).

However there is limited research concerning the experience of dementia from the perspective of whole families. Studies by Garwick et al (1994) and Roach et al. (2014b) are two of only a small number that have addressed the *family* experience and explicitly acknowledged the need for such a focus. Furthermore, family centred interventions have rarely been adopted within dementia care (Benbow and Sharman 2014). Indeed it is suggested that the focus of care services has commonly been on 'caregiving' thus reducing relationships to a functional role involving care for the person with dementia (Roach et al. 2014b; Braun et al. 2009). A risk of this reductionist approach is that the person with dementia is also reduced to the role of 'care-recipient' with the resulting loss of power that this can entail (Wadham et al. 2016).

Research into living with other health and long-term conditions supports the suggestion that a focus on family relationships would be beneficial. For example, Kissane and Bloch (2002) describe family focused grief interventions for families affected by cancer. Similarly, Fadden and Smith (2009) describe family interventions in the context of psychosis. A recent review has confirmed the value of family interventions in schizophrenia in reducing relapse rates and admission to hospital (Bucci et al. 2016). Nevertheless it would be inappropriate to transfer family experiences of these conditions given the differences associated with dementia, such as the unpredictable, lengthy and changing course (Sheilds 1992). Consequently, given the limited evidence concerning the reciprocal influence between family relationships and dementia, it is necessary to develop our understanding of the whole family experience. I aimed to address this in the current study by

involving all core family members as defined by the person with dementia and his/ her care partner.

Furthermore, the development of our understanding needs to acknowledge that dementia is not a unitary experience and that less common forms of dementia and dementia occurring at a younger age involve special needs that are currently under-researched and under-served. Thus a focus on family relationships in this context is an important step forward in advancing the knowledge base and ultimately informing interventions. In the current study, I have taken this into account by focusing on bvFTD, a particular and rare form of dementia that has a younger age of onset than that of the more common forms of dementia.

1.3 What is Dementia Syndrome?

Considerable support exists for a holistic, biopsychosocial construction of dementia in which the person and their family are not defined by dementia but live with it (Kitwood 1997; Brooker 2007; Nolan et al. 2002; Spector and Orrel 2010). A biopsychosocial construction of dementia involves consideration of the multiple factors that influence the lives of the person and their family, including for example, their biography, their health, the relationships they have and the nature of the neurological changes they experience (Kitwood 1997). A biomedical formulation of dementia is an important feature of this construction and contributes to our understanding of the person's experience of living with dementia.

Accordingly, within this biomedical formulation, dementia is considered to be an "*acquired deficit of cognitive function(s) which may include complex attention, executive ability, learning and memory, language, visuospatial-perceptual ability praxis and social cognition. The cognitive deficits may or may not be accompanied by behavioural disorders and must be sufficient to interfere with functional independence"* (Sorbi et al. 2012: 1160-61)

Furthermore, dementia is a progressive and degenerative condition which is life limiting, particularly for younger people below the age of 65.

Establishing a diagnosis of dementia at any age, is a complex process that requires integration of the results of screening assessments, imaging and

neuropsychological assessment together with knowledge of the person with suspected symptoms. Knowledge of the person necessarily includes their usual and current level of functioning and their history. Diagnosis, particularly early in the experience of cognitive and other symptoms is not straightforward and variations in the manifestation of symptoms are commonplace (Eschweiler et al. 2010). Accordingly, active involvement of the person with symptoms and their family members is essential to ensure that the process is inclusive and rigorous. A clinical diagnosis of dementia typically follows a two-stage process, identifying the presence of dementia syndrome and then determining the subtype (Eschweiler et al. 2010).

Although there are acknowledged to be over 100 different types of dementia (Milne 2010) the most common forms are listed in the table below (table 1.1):

Table 1 Dementia Subtypes	
Alzheimer's Disease accounting for 62% of all dementia diagnoses	Alzheimer's disease can be further split into the following subtypes although the amnestic presentation is the most common • Amnestic (Primary impairment in memory plus at least one other cognitive impairment) • Executive dysfunction (Primary impairment in reasoning, judgement and problem solving) • Posterior Cortical Atrophy (PCA) (Primary impairment in spatial cognition) • Language presentation (Primary impairment in word finding)
Vascular Dementia Accounting for 17% of all dementia diagnoses	
Mixed Alzheimer's disease and vascular dementia accounting for 10% of all dementia diagnoses	
Dementia with Lewy Bodies or Dementia associated with Parkinson's disease	

Accounting for 6% of all diagnoses	
Frontotemporal Dementia Accounting for 2% of all diagnoses	Frontotemporal dementia is split into the following subtypes although bvFTD is the most common 1. Behavioural variant FTD (bvFTD) 2. Primary Progressive Aphasias; a. Semantic Dementia (or Semantic variant PPA) (SD) b. Progressive non-fluent aphasia (PNFA) c. Logopenic Aphasia (LA)

(Knapp and Prince 2007; McKhann et al. 2011; Rascovsky et al. 2011; Snowden et al. 2011; Gorno-tempini et al. 2011).

As can be seen above, significant variation exists in the types of dementia that are most commonly diagnosed and as indicated earlier, variability in symptom experience, even within these subtypes is not uncommon. However dementia is not well understood and is commonly associated with memory loss (Alzheimer's Research UK 2016). Consequently, people who live with less common forms of dementia, as identified in table 1.1, may struggle to gain a diagnosis and appropriate advice and support. Furthermore their needs may be less well understood by others within their family, social circle and community. It is for these reasons and the challenges I experienced in my clinical role that I have chosen to focus on bvFTD in this thesis.

1.4 Structure of the thesis

In Chapter 1, I have considered my personal reasons for undertaking this research. I have provided an overview of the background and context to this research study and have briefly introduced the demography influencing current policy in regard to dementia. I have summarised the reasons why a focus on family relationships could be beneficial. Finally, I have provided an overview of dementia syndrome.

In Chapter 2 I provide an integrative literature review. In the introduction, I summarise the existing literature concerning family relationships and dementia. Following this, I present a systematic synthesis of qualitative research exploring the reciprocal influence between dementia and family relationships. Articles which have been published since the synthesis was

completed for publication in 2012 are added to the review to ensure that it is up-to-date. I then describe behavioural variant frontotemporal dementia, considering the key features of the condition and its psychosocial impact. Finally, I review relevant literature concerning the impact and experience of living with bvFTD for both the person with dementia and family members.

In Chapter 3, I review the epistemological and ontological position of this research and provide a rationale for the methodology chosen for this study.

In Chapter 4, I provide a description of the methods, including the process of ethical approval, recruitment, data collection and analysis. I also provide an overview of the participating families.

In Chapter 5, I provide an introduction and overview of the results

In Chapter 6, I present the findings associated with the first superordinate theme; *Cohesive and connected --- Disconnected and distant* which concerns the nature of families prior to the onset of bvFTD. I provide a summary portrait of each family and individuals within the family of their relationships prior to the onset of bvFTD. Furthermore, I offer an account of the interview context for each family and consider my influence on the research.

In Chapter 7, I present the findings associated with the second superordinate theme; *challenges to we/ I* which encapsulates the four challenges that the seven families experienced in living with bvFTD. Two challenges were experienced by the whole family; *awareness and understanding of the changes* and *managing everyday life*. One challenge was experienced by partners and adult daughters; *we're not the same anymore*. A final challenge was experienced by the person with bvFTD; *being me in the context of bvFTD.* I also consider the influencing elements associated with each of these challenges.

In Chapter 8, I present the findings associated with the superordinate theme *assimilating, adjusting and reconstructing --- resisting, denying or being stuck* which addresses the psychosocial and practical coping processes used by these seven families to manage the impact of the challenges described in Chapter 7.

In Chapter 9, I present the findings associated with the final superordinate theme; *A changing we / I ---- An entrenched we / I*. This relates to the relational outcomes associated with the experience of bvFTD for these seven families.

In Chapter 10, I explore the links between the current study and the systematic synthesis described in Chapter 1. I also consider the added value this study brings to existing research as well as exploring the limitations of the study. Finally, I discuss the implications of these results for research and for interventions to support families to live well with bvFTD.

Chapter 2: Literature Review

2.1. Introduction

In this chapter I present an integrative literature review to provide a preliminary conceptualisation of the interplay between relationships and dementia, given that research in this field is at an early stage of development (Torraco 2005). The review is divided into ten sections. After describing the method for the review in section 2.2, I outline the search strategy for family relationships and dementia in section 2.3. In section 2.4, I summarise existing research concerning the connections between family relationships and dementia, the majority of which focuses on those in relationship with a person with dementia such as a partner or adult child.

In section 2.5, I present the findings of a systematic synthesis of qualitative research which explores the reciprocal influence of dementia and family relationships which includes the person with dementia. This synthesis was undertaken in 2012. Much of the research to that date that had explored the impact of dementia on relationships involved in-depth, qualitative studies that had rarely been included in systematic reviews. The goals of the review were to illuminate what was known about reciprocal influences between family relationships and dementia from the perspectives of the family (including the person with dementia); and to consider the implications of these findings for research and practice. A thematic analysis was conducted of 11 qualitative articles considering the impact of dementia upon relationships. The findings were written up for publication in Ageing and Society and the article was published in 2014 (La Fontaine and Oyebode 2014). This thesis will describe the search strategy; summarise the findings of the review and explore the implications for research. As the synthesis was completed in 2012, a further search was undertaken to establish any additional qualitative studies published since that date. These studies are also reviewed.

In sections 2.6 to 2.9, I move on to consider behavioural variant frontotemporal dementia (bvFTD) more specifically. Section 2.6 provides an overview of behavioural variant frontotemporal dementia (bvFTD), summarising the main features of the condition. Section 2.7 describes the

search strategy for this section of the review. Sections 2.8 and 2.9 of the review involve an analysis of research which considers the specific experience of bvFTD for the person with dementia and for family members. Finally, in 2.10 and 2.11, the results of these sections are combined to consider the gaps in current research and therefore the aims of this current study.

2.2 Method

Integrative literature reviews are suggested to be a particular method of review that can provide a comprehensive conceptualisation of a specific area (Whittemore and Knafl 2005) by bringing together different sources of evidence including experimental and qualitative research.

One widely accepted approach to conducting an integrative review is to follow a set of steps that seek to demonstrate methodological rigour. These are as follows:

1. Problem formulation
2. Literature search
3. Data evaluation
4. Data analysis
5. Presentation (Whittemore and Knafl 2005)

While I have broadly followed these steps for the whole review, they have been specifically applied to sections three, five and six to nine.

2.3 Search Strategy Family Relationships and Dementia

In order to establish what was known about how dementia influences family relationships and vice versa, a search strategy was devised that involved the process described in table 2.1. The searches were originally conducted in 2012 and were updated in 2016. A systematic synthesis of the reciprocal influence of family relationships and dementia was written using the findings of the 2012 search and was published in Ageing and Society (see appendix 1 PDF on CD). I have quoted extensively from this article on pages 29-44 as permitted by university regulations and with permission from Cambridge University Press.

Table 2.1: Search Strategy Family Relationships and Dementia
Keyword Search: Dementia OR Alzheimer's Disease AND Caregiv* or Carer AND/ OR Family Relations* or Relations*, Parent Child relations*, Marriage or Marital Relations*, Spouse, Spousal Relations*, Sexual Relations*, Child*, Couplehood, Spousal Caregiv*, Mother Daughter Relations* Mother Son Relations*
Databases Searched: 1) Ovid Search of PsycARTICLES, PsycINFO, CAB, Embase, Medline, = individual searches combined resulting in 350 articles after duplicates were removed 2) Cinahl, = 157 articles after duplicates removed 3) Web of Science = 367 articles 4) ASSIA = 1 article (Limits applied: English language)
Inclusion Criteria: 1) This review is concerned with understanding the impact of dementia upon family relationships including the person living with dementia, therefore the presence of these factors should be a central feature of the article 2) Qualitative methodology, as the purpose is to develop an in-depth understanding of the impact of dementia upon relationships 3) Actual research studies rather than systematic reviews or literature reviews
Exclusion Criteria 1) Studies using a quantitative methodology as such methods are concerned with breadth and generalisability rather than in-depth understanding 2) Articles that focused upon relationships between people living with dementia and their families and health and social care staff 3) Use of observational methods rather than qualitative interviews
Search repeated July 2016. Limited to dates between 2012 and current date 278 abstracts were retrieved after duplicates removed A hand search of Dementia and the references used identified a further 2 articles.

In the original search in 2012, all articles obtained were subjected to initial review based upon the title and abstract. Eighteen articles were identified as relevant. A further hand search of these articles and of the journal Dementia, identified a further five articles for inclusion. The full text of twenty three

articles was then subjected to further scrutiny, to assess their inclusion according to the criteria outlined in table 2.1 above.

Eleven articles were selected as meeting the criteria. Their methodologies, research questions and key results are summarised in appendix 2 (PDF CD). Eight of the studies had the relationship between the person with dementia and their family member as a central theme (Daniels et al. 2007; Davies 2011; Forbat 2003; Hellström et al. 2007; Hellström et al. 2005; Molyneaux et al. 2011; Purves 2010; Ward-Griffin et al. 2007) . The other three included methods and results which illustrated the participants' reactions to and experiences of dementia and its impact upon their dyadic relationship (Clare and Shakespeare 2004; Robinson et al. 2005; Svanström and Dahlberg 2004).

In July 2016, the searches were updated using the same process. Abstracts and titles of articles retrieved from the second search (see table 2.1) were evaluated. Full text was obtained for seven articles which were subjected to further scrutiny. Of these, four were selected as meeting the criteria (Roach et al. 2014a; Hydén and Nilsson 2015; Wawrziczny et al. 2014; Merrick et al. 2016). Their methodologies, research questions and key results are also summarised in appendix 2 (PDF CD). All four studies had relationships between the person with dementia and their families as the central theme.

Articles retrieved from the initial searches that had relationships as their central theme, but used quantitative methodologies, were systematic reviews or meta-syntheses, or did not include the perspective of the person with dementia were retained to set the context for the synthesis. In this next section, I begin by reviewing these papers, which draw upon a wide range of recent research on caregiving, relationships and dementia. Following this the results of the systematic synthesis are presented.

2.4 Existing research concerning the reciprocal influence of dementia and relationships.

Systematic reviews addressing caregiving and relationships

Various authors emphasise that dementia occurs in the context of a pre-existing relationship that continues to develop over time, evolving

dynamically as developmental transitions and challenges occur over the life cycle (Ablitt et al. 2009; Woods et al. 2001; Whitlach 2001; Quinn et al. 2009). As indicated in Chapter 1, most research concerning the reciprocal influence of dementia and relationships is relatively recent (Ablitt et al. 2009). Studies prior to 2008 primarily considered the perspectives of family caregivers, predominantly spouses (Quinn et al. 2009; Ablitt et al. 2009). More recent research has extended to considering other family members, including adult children, children and young people. Furthermore, research has also begun to consider the views of people living with dementia about their relationships.

Two systematic reviews of the interrelationship between dementia and relationships were published in 2009 (Ablitt et al. 2009; Quinn et al. 2009). Additionally, a review considering the dyadic perspective in dementia caregiving in spousal relationships was also published (Braun et al. 2009). These three reviews considered the findings of a total of 38 studies (27 quantitative, 11 qualitative), thirteen of which were common to all of the reviews.

These systematic reviews identified a number of relevant findings addressing:

- The impact of dementia on relationships
- The impact of the relationship on living with dementia
- The influence of the caregiving relative on the quality of the relationship between the person with dementia and the caregiver
- The impact of the quality of the relationship between the person with dementia and the family caregiver on the wellbeing of them both

Each of these reviews has concluded that the research studies they have reviewed are largely taken from the perspective of the family caregiver. The reviews suggest that current relationship quality is evaluated as having declined overall in the context of dementia when compared to prior relationship quality (Quinn et al. 2009; Ablitt et al. 2009; Braun et al. 2009). Specific areas of decline include intimacy, reciprocity, communication and happiness. Conversely however, two of the reviews emphasise that some

studies found an increase in closeness, warmth and mutual affection. They further suggested that maintaining a sense of mutuality was an important influence on the experience of the person and their family caregiver throughout the time they live with dementia (Ablitt et al. 2009; Braun et al. 2009). In some of the studies reviewed, changes in the quality of relationships were noted over time, confirming the dynamic and longitudinal nature of the reciprocal influences between dementia and relationships. Thus the impact on current relationship quality appeared to be nuanced, subject to change and involved potential losses and gains.

These reviews also considered the influence of the quality of the relationship prior to the onset of dementia. A close prior relationship was positively associated with the wellbeing of the caregiving relative. In this context, caregiving relatives were found to experience lower burden, less depression, greater satisfaction and increased mastery (Quinn et al. 2009; Braun et al. 2009; Ablitt et al. 2009). These factors appeared to positively influence the caregivers' response to the person with dementia, with one review suggesting that the caregiving relative was less likely to be abusive and that there were fewer changes reported by the caregiver in memory and personality of the person with dementia (Quinn et al. 2009). Conversely, a poor prior relationship was associated with higher levels of depression, strain, poor quality of life and caregiving satisfaction (Quinn et al. 2009).

It also appears that current relationship quality impacts upon the wellbeing of the family caregiver and the person with dementia. Findings of one review demonstrated that poor current relationship quality was positively correlated with higher levels of depression, strain and lower self-efficacy in caregiving (Ablitt et al. 2009). Conversely, closer current relationships were found to have a positive effect on the caregiving relatives' physical health (Quinn et al. 2009). However one review noted that better quality communication between couples was associated with distress in the caregiving relative and high levels of cohesion were associated with high resting blood pressure (Ablitt et al. 2009). Consequently, it cannot be assumed that all family caregiving relationships will follow the pattern described above. Nevertheless, the quality of the current relationship was found to be associated with wellbeing

in the person with dementia and to support their problem solving ability and task performance. Thus it appears that a positive relationship can also have beneficial effects for the person with dementia (Quinn et al. 2009; Ablitt et al. 2009).

Finally, all the reviews considered the small body of research which included the perspectives of both the person with dementia and their caregiving relative upon each other. Two reviews reported that people with dementia rated their current relationship with the caregiving relative more positively than their relative did (Ablitt et al. 2009; Quinn et al. 2009). However Ablitt et al. (2009) noted that, as with their caregiving relatives, those with dementia also experienced a process of adjustment and adaptation, involving initial withdrawal after diagnosis followed by efforts to work together to maintain their relationship. Braun et al. (2009) also reported findings suggesting that insecure attachment styles of the person with dementia and avoidant attachment styles of the spouse resulted in higher levels of problematic behaviours being experienced by the spouse caregiver.

These reviews have highlighted a number of methodological limitations in existing research in this area including:

1. That studies had reported conflicting results concerning the experiences of caregiving relatives,
2. were limited because of their cross-sectional design and;
3. had not addressed both prior and current relationship quality (Quinn et al. 2009; Braun et al. 2009).

Additionally, Quinn et al. (2009) suggested that existing theoretical models relevant to caregiving do not fully account for the influence of prior and current relationship quality on carer wellbeing. Furthermore, models that can facilitate an understanding of the caregiving experience within a relational context had not been applied (Ablitt et al. 2009).

In many of the studies reviewed, the experiences of caregivers are taken as a whole without consideration of the differences that may occur related to the nature of the relationship between the person with dementia and their caregiver, the gender or culture of the caregiver. While Quinn et al. (2009)

suggest that evidence is conflicting; a number of authors conclude that there are differences (Pinquart and Sörenson 2011; Braun et al. 2009; Savundranayagam, et al. 2010; Kwak et al. 2012). For example, spousal caregiving may not initially be considered as caring by spouses and may be connected to the bonds and the commitment that couples had made to each other (Camden et al. 2011; Hellström et al. 2007a; Barnes et al. 2016). Furthermore, evidence suggests that spouses may incur greater negative outcomes from caregiving including higher levels of depression (Pinquart and Sörenson 2011; Shim et al. 2012).

Additionally, other research suggests that gender also influences coping styles (Savundranayagam. et al. 2010; Kwak et al. 2012; Calasanti and King 2007). For example, female spouse caregivers may experience greater levels of stress and burden and are thought to use more emotion focused coping (Etters et al. 2008). Conversely, male caregivers are suggested to be more likely to use coping strategies such as problem solving, treating caregiving roles as 'work' (McDonnell and Ryan 2011; Pöysti, et al. 2012; Pretorius et al. 2009).

It seems necessary therefore to consider gender and relationship type in order to obtain a better understanding of the factors influencing experiences.

Summary

It appears from these systematic reviews that the evidence concerning the reciprocal influence between dementia and relationships is developing. Furthermore, it seems that outcomes for the caregiving relative and the person with dementia are nuanced and complex and do not necessarily follow a predictable pattern. However existing research is hampered by a number of methodological limitations. These include the lack of consideration of, or controlling for, different caregiving relationships and gender. Furthermore, the perspective of the person with dementia is absent in many research studies. Consequently, there are important areas identified which require further study. These reviews suggest that studies need to be informed by and inform theoretical frameworks of caregiving and that prior and current relationship quality need to be included as factors influencing the

experience of dementia. A further recommendation was that future research in this area needed to include the perspectives of people living with dementia. I now turn to research considering the perspectives of individual family members concerning dementia and relationships.

The perspectives of spouses

Recently, there has been an increase in published research concerning spouses' perspectives on the impact of dementia on their relationship with their partner. As qualitative research is concerned with depth rather than breadth, their results are not generalisable. Nevertheless they do offer necessary depth to our understanding. Similarly, quantitative studies have considered the impact on the relationship, although there are acknowledged limitations to this research including sampling and cross sectional designs. Furthermore, the majority have considered the experience of Alzheimer's disease and where people with other forms of dementia have been included; their experiences have been amalgamated without considering whether there might be differences associated with specific forms of dementia. Recent qualitative and quantitative studies and meta-syntheses of qualitative research are now considered.

It is suggested that the impact of dementia upon spouses who provide care for a partner with dementia is particularly significant because they represent the largest group of people caring for those living with dementia. Evidence also suggests that they are the group who are most vulnerable to poor health outcomes (Shim et al. 2012; Camden et al. 2011; Barnes et al. 2016). Spouse caregiving usually occurs in the context of a longstanding relationship. However, spousal caregiving increasingly represents a diverse group involving second relationships, partnerships and lesbian and gay relationships. Additionally, the experiences of spouses of younger people with dementia may be different from the older majority (Svanberg et al. 2011; van Vliet et al. 2010). Diverse relationships and groups are significantly less well represented in the literature, thus this section is largely limited to considering the perspectives of older, predominantly female spouse caregivers in longstanding relationships.

Research suggests that spouses who provide care, experience significant challenges to their relationship with their partner as a consequence of dementia (Shim et al. 2012). These challenges include losses associated with the changes in their partner and therefore the changes in their relationship (Pozzebon et al. 2016; Lin et al. 2011). Spouses who provide care experienced significant changes in role, taking on roles previously undertaken by their partner (Youell, et al. 2016; Pozzebon et al. 2016; Lin et al. 2011; Shim et al. 2012). Spouses of younger people with dementia reported additional difficulties associated with their life stage, including feeling that they have been denied the hoped for future with their partner (Alzheimer's Australia 2007).

Despite these challenges, spouse caregivers are identified as reporting higher pre-caregiving relationship quality and to have higher levels of intrinsic and extrinsic motivations and meanings associated with caregiving when compared with other relationship types (Quinn et al. 2012). Quinn et al. (2012) identified that male spouse caregivers were particularly likely to report higher pre-caregiving and current relationship quality. Nevertheless, while many spouses sought to maintain continuity in their relationship with the person with dementia, it appeared that they also recognised that this was increasingly difficult to retain over time (Pozzebon et al. 2016). This realisation resulted in changes in self-concept for many partners, reflecting a shift from partner to caregiver (Pozzebon et al. 2016; Lin et al. 2011). Struggles associated with this change included experiencing isolation and loneliness as the relationship had fundamentally altered.

A number of factors were found to influence the manner in which caregiving took place. Adaptation and adjustment was an ongoing process and framed within the context of the past relationship, the qualities of the person with dementia, the spouses' understanding of the impact of dementia and their ability to attune their responses to their spouses' needs (Pozzebon et al. 2016; Lin et al 2011; Lloyd et al. 2014; Shim et al. 2012). Where a positive prior relationship existed, spouses were motivated to care, they found caregiving meaningful, they often saw their actions in the context of maintaining their togetherness and were driven by the commitment they had

to their spouse (Quinn et al. 2012; Pozzebon et al. 2016; Lin et al. 2011, Lloyd et al. 2014; Shim et al. 2012). Acceptance of the changes was fundamental to their ability to maintain connectedness (Pozzebon et al. 2016; Lin et al. 2011; Lloyd et al. 2014; Shim et al. 2012). In this context it appears that spouses described increased companionship in their relationship with the person with dementia (Lloyd et al. 2014; Shim et al. 2012). However, in the context of a previously poor relationship, caregiving was associated with positioning the person with dementia as the problem. As a result spouses perceived the person as at fault for their behaviour and were focused on their own needs rather than those of their partner. (Lin et al. 2011; Shim et al. 2012). Furthermore, it appeared that those with a negative past and current relationship report higher levels of burden (Shim et al. 2012).

While the evidence above might imply that spouses' experiences are largely positive or negative, longitudinal qualitative studies in particular suggest that it is not as polarised as this and that spouses may oscillate between these opposite poles over the duration of their caregiving (Lin et al. 2011). Furthermore, Fauth et al. (2012) suggest that over the duration of the caregiving experience, closeness in the relationship may be associated with poorer physical and mental health outcomes. They suggested therefore that for some spousal caregivers, distancing may be an adaptive strategy to cope with the changes in their partner (Fauth et al. 2012). Consequently, it seems that the experience of caregiving is not a linear process but reflects a constant process of change, adaptation and adjustment with dementia over time.

Finally, in some studies, family support to spouses was considered. In their qualitative synthesis, Pozzebon et al. (2016) suggested in one study that some spouses were unwilling to share with other family members because they did not wish to burden others. However another study suggested that spouses found family support to be particularly helpful, providing opportunities to express emotions, have a break from caring and help with the tasks of caring (Lin et al. 2011). Additionally, it appears that spousal caregiving in the context of late life remarriage could be associated with

intergenerational conflict and rejection in relationships with step children and own children (Sherman and Boss, 2007). These authors found that relationship difficulties caused these wives to feel alone in caregiving both practically and emotionally in their role.

Summary

The results of these studies appear to be congruent with the systematic reviews described above. In addition to those already described, there are methodological limitations in the qualitative research that need to be taken into account. For example, Pozzebon et al. (2016) suggest that the demographic characteristics of participants are not always adequately reported which makes it difficult to consider their transferability. Nevertheless, the studies do provide further depth to our understanding of the nuanced experience of spouses concerning the impact of dementia on the relationship with their partner. Consistent with the results of the systematic reviews, prior relationship quality seems to influence current relationship quality for spouses. It seemed that the impact on relationships involved both significant losses and potential gains. Losses were framed in a relational context, thus changes in the person with dementia were described in terms of how they impacted on their relationship (Pozzebon et al. 2016). In the context of a previously positive relationship, many spouses sought to maintain connectedness and mutuality in their relationship and could experience satisfaction in their caregiving role. Nevertheless, it appeared that spouses engaged in a continual process of adjustment and adaptation and over time were at significant risk of loss of identity, isolation and loneliness. Some spouses were able to rely on and valued family support but not all were able to. Where relationships were conflictual or support was absent, this increased isolation. The experiences of spouses with previously poor relationships seem to be less well represented in the literature.

The perspective of people with dementia

Studies directly considering the perspective of people living with dementia have only recently emerged. However some studies have considered how people living with dementia expressed their sense of self or how they lived

positively with dementia and their findings identify the importance of family to those participating. Participants suggested that they valued family most in life; appreciated the support offered to them and expressed concern about the challenges that dementia would bring for their family (Wolverson, et al. 2016; Hedman et al. 2013). Furthermore Wolverson et al. (2016) suggested that people with dementia strived to maintain connectedness and continued to value their relationships with significant others.

Ablitt et al. (2010) found that a significant proportion of the participants with dementia they interviewed were aware of the psychological wellbeing of family members who support them and some were aware of their family caregivers' level of anxiety. Furthermore, some were able to relate their caregivers' distress to the impact of caring and were able to be more supportive of their caregiver as a consequence.

Ward-Griffin et al (2006) considered the perspectives of women living with dementia about their relationships with their caregiving daughters. They found that the women mostly reported a positive relationship with their daughters. However it was also evident that they did not want to be a burden and engaged a number of strategies to resist this, including caring for themselves as much as they could and asking as for as little as possible. They described deciding what level of care they would accept from their daughters while accepting and being grateful for care when this was offered.

Summary

The few studies that consider the perspectives of people living with dementia about the impact their condition has on their relationships suggest that people with dementia value their relationships with family and recognise that dementia brought challenges for their family. Some actively engaged strategies to manage the impact on their relationships, offering support to their partner, managing the amount of support they expected or asked for and expressing gratitude for the care that was given. There is a need to address the experiences of a wider range of people living with dementia, for example those with experience of more advanced dementia, those from migrant communities and those with different relationship types

(Wolverson et al. 2016), as well as those who have more negative relationships. However, a particular value of these studies is that they demonstrate that people with dementia can contribute to qualitative and quantitative research on relationships.

The perspective of adult children and young people

Adult children and young people can be divided into two subgroups in regard to the existing research in this area:

- Adult children in midlife who are caring for an older parent with dementia, either solely or as a secondary caregiver supporting their other parent
- Young adult children and young people who commonly have a parent with young onset dementia, who may or may not be involved in caregiving but may be dependent emotionally and/or financially on their parents due to their age.

The perspectives of these two groups are addressed separately below.

Adult children in midlife

Daughters are the most common caregivers for people living with dementia after a spouse and social norms have a particular influence, involving for example gendered expectation of who will care within families (Quinn, et al. 2010; Alzheimer's Society, 2011). Nevertheless, in recent years it is recognized that sons are also increasingly involved in caregiving (McDonnell and Ryan 2011). Children-in-law are also providing care although less frequently (Pinquart and Sörenson, 2011). Adult child caregivers generally live separately from the person with dementia and are likely to have other demands on their lives including family, financial and employment responsibilities (Schoenmakers et al. 2010; Alzheimer's Society 2011; Pinquart and Sörenson, 2011).

Relationships between parents and adult children are complex and multifaceted. Cultural and family norms regarding individuation, independence and reciprocity influence the caregiving experience (Dykstra and Fokkema 2011, Kjällman-Alm et al. 2013). Providing care in this context

is associated with many challenges, involving changing roles and responsibilities in adult children's relationship with parents with dementia, which are grounded in the quality and nature of the past relationship. Additionally, caregiving responsibilities impact upon other relationships in the adult child's life, including with their partners and children (Pinquart and Sörenson 2011; Piercy 2007; Sechrist et al. 2012; McDonnell and Ryan 2014; Sherrell et al. 2001).

Adult children are motivated to care due to past and/or current relationship closeness, from a sense of duty or because they live in close proximity (Camden et al. 2011; McDonnell and Ryan 2011; McDonnell and Ryan, 2014; Ward-Griffin et al. 2007; Piercy 2007). The quality of the previous relationship appears to have a significant influence on current relationship quality and the outcomes associated with caregiving for both children and their parents (Ward-Griffin et al. 2007; Piercy 2007; McDonnell and Ryan 2014). Evidence suggests that previously positive relationships can continue to be meaningful for both the parent and the child. However in addition, it seems that the need for care can cause past conflicts and difficulties to re-emerge which may cause conflict in the current relationship. (Ward-Griffin et al. 2007; McDonnell and Ryan 2014; Sherrell et al. 2001).

The current relationship with the parent is complicated by normative boundaries, for example it may be expected that parents would continue to support the welfare of their adult children (Sechrist et al. 2012). Yet in some studies, adult children reflect that they now feel they are 'parenting' their parent with dementia (Kjällman-Alm et al. 2013; Sherrell et al. 2001). This change may be associated with feelings of abandonment, loss and anger, as well as yearning for the past relationship (Kjällman-Alm et al. 2013).

The impact of caregiving on adult children is known to be significant. Negative outcomes include increased stress, poor physical and mental health and undesirable changes in the relationship with the parent with dementia (Pinquart and Sörenson 2011; Kwak et al. 2012; Savundranayagam et al. 2010). These outcomes are associated with an increased risk that the person with dementia will be placed in long term care, particularly where the behaviour of the parent with dementia is experienced as difficult

(Savundranayagam, et al. 2010). Furthermore, adult child caregiving is correlated with greater levels of wider family conflict, as adult children may expect help and assistance from other family members and experience conflict when this isn't forthcoming (Kwak et al. 2012; Alvira et al. 2015; Tolkacheva et al. 2011). Children-in-law may experience less satisfaction with caregiving, possibly because they are likely to have less closeness with the person with dementia (Pinquart and Sörenson 2011).

Summary

As with the previous two sections there are methodological limitations to existing research. In particular, McDonnell and Ryan (2014) emphasise the need for more studies which specifically explore the relationship between sons and their parent with dementia. Furthermore, it seems that longitudinal quantitative and qualitative studies would further enhance our understanding, as many of the studies reviewed here are cross-sectional.

Nevertheless, research evidence suggests that there are differences in the experience of caregiving for midlife adult children when compared with spousal relationships. Furthermore, it appears that social and familial norms influence the nature of the relationship and caregiving in this context. Previous and current relationship quality are important factors influencing the experience of dementia for both the adult child and their parent. While satisfactions may be present, it also appears that adult children experience complex emotions concerning the changes in their parent. When combined with the challenges engendered by caregiving this can lead to negative outcomes, including poor physical and mental health, conflict in family relationships and placement of the person in long term care.

Young adult children

This research is a relatively recent addition to the literature and largely reflects an increasing need to develop an understanding of the experience and needs of young people who have a parent living with young onset dementia. These studies are generally qualitative in nature and reflect the specific difficulties associated with the life stage of young people. This includes that they are often living with or still financially dependent upon their

parents, may still be in full time education and may be negotiating their own development transitions (Hutchinson et al. 2016; Allen et al. 2009; Lage Barca et al. 2014; Sikes and Hall 2016). Given the numbers of younger people living with dementia, the samples of young people recruited to these studies is diverse and small in number. Most of the participants were over the age of 18, although for some their parent's illness began before they reached this age. Three of the studies included children below the age of 18 but the numbers of these were significantly smaller (Allen et al. 2009; Hutchinson et al. 2016; Sikes and Hall 2016). The age range of the participants included children as young as 10 and young adults as old as 33. There are inevitably difficulties in combining the results of interviews with young people who are at different developmental life points (Allen et al. 2009).

These studies all emphasise the changes that participants experienced to their family relationships (Hutchinson et al. 2016; Allen et al. 2009; Lage Barca et al. 2014; Sikes and Hall 2016). Relationships with their parent with dementia were fundamentally altered as a consequence of dementia and young adults and children described the person as not the same or not their 'real parent' (Allen et al. 2009, Sikes and Hall 2016). Participants described a profound sense of loss at the changes in their parent (Hutchinson et al. 2016; Sikes et al. 2016). Furthermore, changes in relationships with their 'well' parent were also discussed, as young people seemed to balance caregiving responsibilities and a sense of being responsible for their well parent with their own needs and development transitions (Allen et al. 2009; Lage Barca et al. 2014).

Outcomes for these family members involved physical strain including lack of sleep (Allen et al. 2009). Similarly psychological strain was also identified. This included fear of losing the well parent due to the level of strain they were experiencing, being unable to focus on their own needs and overwhelming emotions associated with the changes. On occasions this lead to self-harming behaviour (Allen et al. 2009; Hutchinson et al. 2016; Sikes et al. 2016; Lage Barca et al. 2014). Furthermore, some identified that there had been a breakdown in relationships within the family as a consequence.

In two studies this resulted in the adult child or young person distancing themselves emotionally and sometimes involved leaving the family home at a time when they were potentially highly vulnerable (Hutchinson et al. 2016; Allen et al. 2009).

Summary

Only a small number of studies consider the experiences and perspectives of young adult children and young people and these draw on a wide age range. Their results suggest that dementia in a parent impacts significantly on relationships with both parents. Due to the life stage of these participants they are often reliant on their parents for financial, practical and emotional support. The experience of dementia in this context seems to disrupt normative developmental transitions and involve participants in increased responsibility for the parent with dementia as well as increased concern for the well parent. Negative outcomes are considerable, involving psychological and physical strain.

Conclusion

The studies reviewed above offer an insight into the reciprocal influence of dementia and relationships and demonstrate that a broad range of family relationships are influenced by dementia and in turn influence the way in which dementia is experienced. Additionally, they suggest that family members are active in shaping how they experience dementia and that they influence each other's experience of dementia. For example, it seems that the experience of spouses and adult children can be negatively or positively influenced by the supportiveness of other family members and the extent to which such support is sought and welcomed. Indeed in a recent European study, lack of family support was correlated with poor caregiver outcomes including burden and psychological wellbeing (Alvira et al. 2015).

However they are also limited because they consider the perspective of only one person within the relationship. By their very nature, relationships are negotiated between individuals and as the results above suggest, the onset of dementia is managed within the context of a family, whether that be a marital relationship and/ or an extended family. Furthermore, the

perspectives of people living with dementia have often been excluded from this research, even though the small numbers of studies that do exist demonstrate that they value relationships with their families and actively contribute to them. These findings correspond with the views of Kitwood (1997) and others in confirming that there is a need to consider how dementia impacts upon relationships and how relationships impact on the experience of dementia.

In addition, this research has largely considered the influence of dementia upon couples and has rarely explored the experience for other family relationships, or indeed the relationship of the family as a whole. The above would suggest that the whole family are likely to be affected by dementia and that existing family relationships may influence how dementia is experienced and how it is managed. In light of this, it seems pertinent to consider what the family experience of dementia might be. This next section reports the results of a systematic synthesis which explores family relationships and dementia, including the person with dementia.

2.5 Family Relationships and dementia: a synthesis of qualitative research including the person with dementia

As described earlier, a qualitative synthesis was undertaken in 2012, considering research evidence concerning the reciprocal influence between family relationships and dementia. The synthesis was completed in 2012 and was subsequently published in Ageing and Society. Its methods and findings are reproduced in brief below with the permission of Cambridge University Press (La Fontaine and Oyebode 2014 p.1246-1268).

Following the search strategy described in 2.1, eleven articles were selected for inclusion. Thematic synthesis (Thomas and Harden 2008) was selected as the methodology, since it is suitable for synthesising studies using a range of methodologies (Braun and Clarke 2006).

A range of methodologies, including constructivist grounded theory, discourse analysis and phenomenological methodologies informed ten of the eleven studies with one not stating what sort of methodology was used. In-depth interviews were the main method utilised for data collection, with seven

interviewing participants together. Eight used a cross-sectional design, interviewing participants at one point in time.

In all but three studies the participants were co-habiting couples. The three other studies involved adult-daughter and mother relationships (Forbat 2003; Ward Griffin et al. 2007) or a three-generational family (Purves 2010). Participants were generally recruited from service providers including memory clinics. In eight studies, participants with dementia had received a diagnosis of Alzheimer's disease. In the other studies, diagnoses were dementia, mixed dementia or vascular dementia. In over half, the length of time dementia had been experienced is not clear. With the exception of two studies, the type and level of support services received by participants is not described.

Each article was subjected to an assessment of quality of the research according to the 14 criteria identified by Elliott et al. (1999, see table 2.2).

Table 2.2: Criteria for evaluation of qualitative research studies in psychology and related fields (Elliott et al. 1999: 220)

A Criteria relevant to all research	1	Explicit scientific context and purpose
	2	Appropriate Methods
	3	Respect for participants
	4	Specification of methods
	5	Appropriate discussion
	6	Clarity of presentation
	7	Contribution to knowledge
B Criteria relevant to Qualitative Research	1	Owning one's perspective
	2	Situating the sample
	3	Grounding in examples
	4	Providing credibility checks
	5	Coherence
	6	Accomplishing general vs. specific research tasks
	7	Resonating with readers

The table showing the quality rating of each article is included in appendix 3 (PDF CD). Each article was assessed as: Achieving (y), partially achieving (p) or not (n) achieving the criteria. In order to check the reliability of this process three of the papers were independently rated. This process revealed

agreement on 13/14 ratings on 2 of the 3 papers. On the third, on 8/14 criteria, one rater viewed the criterion as met where the other viewed it as partially met. Discussion occurred to understand the discrepancies and arrive at agreement. Overall it was felt that the system was good enough to give a general overview of the quality of the papers, although it must be recognised that, to some extent this is a subjective process and others might make different judgements on some of the criteria.

The articles were generally considered to be of good quality, meeting the criteria either wholly or partially. Limitations included the lack of representation of different relationships, such as parent-child (of both genders), intergenerational families or gay relationships and different forms of dementia. The age of the person with dementia was rarely reported and the ethnic and cultural background of participants was not addressed in the majority of articles. A final limitation involves the predominant cross-sectional design. As dementia is a dynamic journey in which progressive changes, loss and adjustment is not a static process, a longitudinal design is perhaps more likely to illustrate the impact of dementia.

The articles were uploaded onto NVivo (QSR 2010). Thematic synthesis was applied to the text in the findings sections of each of the papers (Thomas and Harden 2008; Braun and Clarke 2006). As this review was particularly concerned with the participants' perspectives of the impact of dementia upon their relationships, it was the participants' data that was given priority. Only segments of text, therefore, that included quotes of participants were subjected to coding.

Summary of results

Four super-ordinate themes emerged from the synthesis; *a shared history*; *negotiating the impact of dementia upon the relationship*, *openness and awareness* and *shifting sands*. Taken separately, some of the articles present a largely positive or negative account of the impact of dementia upon relationships. In synthesising the accounts, a more nuanced view emerges, reflected in the way that the first 3 themes have both positive and negative poles. Table 2.3 illustrates the spread of themes across the studies:

Table 2.3: Incidence of themes across studies in systematic synthesis							
	Superordinate Theme 1: A shared History		**Superordinate Theme 2: Negotiating the impact of dementia upon the relationship**		**Superordinate Theme 3: Openness and Awareness**		**Super-ordinate Theme 4: Shifting Sands**
	A good life	Disconn-ected	A problem shared	Working apart	Making meaning	Minimising	
Clare et al. 2004	✓		✓	✓	✓	✓	✓
Daniels et al. 2007	✓		✓		✓		✓
Davies 2011	✓	✓	✓		✓		✓
Forbat 2003		✓		✓			✓
Hellström et al. 2007a	✓		✓	✓	✓		✓
Hellström et al. 2005			✓				✓
Molyneaux et al. 2011	✓		✓		✓	✓	✓
Purves 2010			✓	✓	✓	✓	✓
Robinson et al. 2005	✓		✓		✓		✓
Svanström et al. 2004			✓	✓	✓		✓
Ward-Griffin et al. 2007	✓	✓	✓	✓	✓		✓

A shared history

The first super-ordinate theme, *A Shared History*, involved 2 subthemes, *a good life together and disconnectedness*. Eight articles contributed to this theme, the majority of which addressed couple relationships.

A good life together appeared to reflect emotional connectedness, in which open communication, negotiation, compromise, sharing of roles and the ability to resolve challenges within the relationship featured. The participants linked their shared positive history with current connectedness and commitment to each other.

Where this was not present, (in two articles exploring mother-daughter relationships and one exploring couple relationships), a negative shared history emerged. This gave rise to the subtheme *disconnectedness* and involved evidence of past conflict and disagreement, which was also evident in the current relationship. Links between past and current relationship quality were made in all the articles addressed in this super-ordinate theme.

Negotiating the impact of dementia upon the relationship

All 11 articles contributed to this super-ordinate theme and two sub-themes emerged, *A Problem Shared and Working Apart*. Under the subtheme of *a problem shared,* it seemed that the diagnosis of dementia and the resulting challenges were viewed as something to be managed together, with participants emphasising their continued commitment to each other and emotional connectedness. Although less frequently, this was also evident in mother-daughter relationships. Furthermore open communication, managing things together and compromise to sustain couplehood was a feature of couple relationships. Participants also reflected upon the importance of mutual respect, appreciation and reciprocity. In the context of their shared lives, in order to manage the impact of dementia and maintain the relationship, participating dyads described various strategies, such as supporting the continuation of valued activities. Strategies sought to maintain the identity and functioning of the person with dementia, sometimes without their knowledge.

However, although evident in only six of the articles and with less frequency, the impact of dementia upon relationships also resulted in family members *working apart*. The way in which this manifested corresponded closely to the

theme of ‘working apart’ described by Keady and Nolan (2003: 30). These authors suggest that where previous relationship quality is poor or where it has not been possible to work together in the context of dementia, the experience leads to strained relationships. Consequently a feeling of entrapment in the family caregiver may also occur.

It appeared in this synthesis that family members and couples experienced a loss of connectedness and may also have experienced feelings of powerlessness and an inability to influence the course of their life. Further breakdown in relationships appeared to occur. Additionally it seemed that the person with dementia was positioned as the problem and strategies such as blaming, deception and confrontation were used.

Openness and Awareness

Nine articles contributed to the third super-ordinate theme, with seven of these concerning couple relationships. *Openness and Awareness* involved the extent to which it was possible for the participants to negotiate and share their understanding of what was happening (sub-theme of *Making Meaning*) or, at the other extreme, minimise it and thus deny the impact of it (sub-theme of *Minimising*). *Making meaning* was illustrated by open communication which included conversations about the changes, even though this might be difficult. Furthermore it appeared that couples in this context saw dementia as the problem rather than the person and sought to live each day as it comes. *Minimising* was illustrated by the use of denial by either or both of the parties in the relationship and seemed to involve denying the experience of the other person and therefore perhaps shielding themselves from the situation or the other’s distress. In such circumstances, individual and interpersonal responses appeared to involve resisting acknowledgement of the reasons for the changes, the eventual diagnosis and the difficulties it brought. Resistance took the form of normalizing the difficulties or actively choosing not to think about them. However not all parties in the relationship were synchronous in their ways of understanding and coping with the changes. Thus on occasions, the strategies of resistance and confrontation were used and appeared to be challenging for both parties,

particularly where this involved a denial of the difficulties experienced as a consequence of dementia.

Shifting Sands...

This final super-ordinate theme addresses the challenges that dementia brought to relationships. All 11 articles included in the review contributed to this theme. Seven articles (one wider family and seven couple relationships) made reference to the change in roles and responsibilities that dementia brought for the relationship. Such changes involved a complex process of negotiation involving noticing and managing the risks associated with changes in the person's abilities; negotiating the forms of help that were needed, while maintaining the identity of the person with dementia. The process of negotiation appeared less challenging where the person with dementia was able to accept that they were no longer able to carry out particular activities or tasks independently. Nevertheless, some family members found this to be a difficult adjustment to make as it entailed extra responsibility.

Early in the experience of dementia, the continuation of valued activities and independent time was possible and desired. However, particularly for couples, the consequence of shifting roles and responsibilities tended to result in couples necessarily having to spend more time together as dementia progressed, rather than being able to spend time on their own independent activities. While spending time together was viewed positively, it appeared also to have negative consequences for wellbeing. Participants expressed the need for time apart and for independence and had difficulty engaging in actions that were previously not part of the relationship. This had the potential to be a source of conflict. Such conflict seemed likely where levels of awareness and openness were not synchronous.

In five articles, reflecting couples, mothers-daughters and wider families, participants' accounts appeared to reflect the loss they experienced as a consequence of the impact of dementia. These accounts were primarily from the family member involved in caring and included losses such as memories of shared history, remembering who the spouse was and changes in roles.

The updated search and analysis

The methodologies of the four additional articles identified in the updated search included Interpretive Phenomenological Analysis (Merrick et al. 2016; Wawrziczny et al. 2014), Narrative Analysis (Roach et al. 2014a) and conversation analysis (Hydén et al. 2016). Hydén et al. (2016) also determined the frequency of use of 'I' and 'we' pronouns. One study involved families (Roach et al. 2014a) and the three others involved couples living with dementia, with two explicitly exploring the experience of young onset dementia (Roach et al. 2014a; Wawrziczny et al. 2014). One study was longitudinal (Roach et al. 2014a) the remainder were cross-sectional. Diagnoses were similar to those in the original studies, although in two of the studies, a participant was diagnosed with frontotemporal dementia and in one study a participant was diagnosed with dementia with Lewy bodies. Length of time since diagnosis was indicated in all four studies and ranged from less than 1 year to 9 years. Articles were assessed according to the quality criteria above and identified as of good quality, meeting the criteria wholly. Limitations were similar to those identified above.

The analysis of the four articles yielded findings that were largely congruent with the original themes of the systematic synthesis. Table 2.4 shows the incidence of themes across the four studies.

Table 2.4: Incidence of themes across studies

	Superordinate Theme 1: A shared History		**Superordinate Theme 2: Negotiating the impact of dementia upon the relationship**		**Superordinate Theme 3: Openness and Awareness**		**Super-ordinate Theme 4: Shifting Sands**
	A good life	Disconn-ected	A problem shared	Working apart	Making meaning	Minimising	
Hydén and Nilsson 2015	✓		✓				✓
Merrick et al. 2016	✓		✓	✓	✓		✓
Roach et al. 2014	✓	✓	✓	✓	✓		✓

Wawrziczny et al. 2014			✓	✓	✓	✓	✓

Three noteworthy subjects emerged from the consideration of these additional four studies. Firstly, a new subtheme of *distancing* arose from the study that explored whole family relationships (Roach et al. 2014a), which contributed to the theme of working apart. This appeared to reflect an intentional distancing between generations (Roach et al. 2014a). Similarly, this was evident in the Wawrziczny et al. (2014) study, when discussing the couples' relationships with their family and wider social circle. It appeared in both studies to be born out of a desire to protect, although the reasons for protection varied. In the Roach et al. (2014a) study, a couple sought to protect their children from the challenges they were facing:

> *"Irene I believe ... I don't know about your Mom and Dad, but I believe that we brought the kids into the world, we don't give them our problems. And we are really, really bad for hiding things". (Roach et al. 2014a: 17)*

This was also cited as a reason in the Wawrziczny et al. (2014) study. However in the latter it also seemed that self-protection against stigma and embarrassment or against the perceived decline in the couple relationship was a motivation:

> *"Couple 16: We try to be discrete. This way, nobody knows, nothing at all, we get by as we can (Person with dementia)" (Wawrziczny et al. 2014: 9)*
>
> *"Couple 06: I could stay home, because I had a planned layoff schedule that I was in and I refused. I got another job that earned me less, but I got the other job because staying home is something I wouldn't know how to do. I still have three years to go and then I'll get my retirement. Afterwards, that's when it's going to be harder. (Caregiver)" (Wawrziczny et al. 2014: 10-11)*

As with the occurrence of the more negative subthemes in the original systematic synthesis, this subtheme was present in only two studies. It seems possible that this arose because both studies considered wider family relationships in the research interviews. However, distancing appeared to have deleterious consequences, increasing the risk of isolation and loneliness.

Secondly, in the Roach et al. (2014a) study, a theme of fabricating storylines emerged from their analysis. This did not feature in any of the other studies and may reflect their use of a longitudinal approach combined with the nature of their research method. This seemed to result in the development of a close relationship between researcher and participants which may have facilitated greater opportunities to reveal life as it is lived and a greater depth of understanding.

Finally, people living with dementia in all four studies reflected on the changes to their relationships and the losses both they and their partners experienced. Furthermore, they described active strategies to mitigate the impact of these losses for their partner:

> *"June Well, really I think that sometimes he gets a bit worried and if he gets worried about things I'll say "yeah that's fine, fine", just so that he doesn't worry about me so much". (Merrick et al. 2016: 46)*

Therefore, these four studies further reinforced the need to involve people living with dementia in such research and highlighted their active contribution to negotiating the impact of dementia within their relationships.

Discussion

The theme of *shifting sands* illustrates the particular psychosocial challenges that dementia brought for all family members in the studies. These included the alterations in roles and relationships and the resulting need for strategies to manage the impact of dementia highlighted in the second and third super-ordinate themes. Recent studies have similarly highlighted the extent to which loss is experienced by family members, involving a loss of 'we' for

couples, (Evans and Lee 2014; Wadham et al. 2016) and for adult children (Madsen and Birkelund 2013; Kjällman-Alm et al. 2013).

Consistent with the findings of the synthesis, the above studies also suggest that family members take increased responsibility as the person with dementia becomes unable to undertake relational work associated with their togetherness. These findings have significant parallels with Rolland's (1994) work on the development of a psychosocial typology of chronic and life threatening illnesses. In particular, indicating that it is necessary to focus upon the duration, course, degree of incapacity and outcome of the changes, the life stage at which they occur and their impact upon the relationships rather than solely on the diagnosis.

This synthesis supports the findings of existing research which emphasises that the nature and quality of the previous and current relationship appear to be important factors influencing the experience of dementia for all family members. Similarly, research suggests that family closeness, reciprocity, love and affection may be important influencers on adaptation to dementia, particularly where family members actively discuss their situation and work together to agree strategies (Deist et al. 2015; Trujillo et al. 2016; Chesla et al. 1994; Sutter et al. 2014; Tremont et al. 2006). Furthermore, although studying specific populations where the values of family are viewed as more important than individual needs, some studies have found that positive family dynamics were correlated with the personal strengths and mental health of family caregivers and have concluded that healthy family dynamics are protective (Trujillo et al. 2016; Sutter et al. 2014; Tremont et al. 2006). This appears therefore to support the value of a focus upon family relationships.

Recent research also supports the superordinate theme of *negotiating the impact of dementia.* For example, as with the theme *a problem shared,* Braun et al (2010) found that awareness of each other's feelings and continued reciprocity was supportive of current relationship quality. Additionally, where the person with dementia was aware of the needs of their partner, this also appeared to contribute to current relationship quality (Spector et al. 2016; Clare et al. 2012). Consistent with the theme of *working apart*, in research where poor relationships were evident in participants, it seemed that working

apart involved an emotional disconnection in relationships, which may contribute to positioning the person as the problem (Chesla et al. 1994; Clare et al. 2012). However some studies suggests that emotional disconnection may be an adaptive strategy, reflecting the need to protect oneself in the face of the changes taking place over time (Clare et al. 2012; Wadham et al. 2016; Fauth et al. 2012). However a limitation of some of the studies reporting such results is that they have not necessarily considered the prior relationship and how this might impact upon current relationship quality. Thus this requires further study.

It seems in the results of the synthesis, that the coping strategies used by family members were important in either providing support to 'scaffold' the identity and self-esteem of the person with dementia or indeed 'position' them in such a way as to undermine their personhood (Kitwood 1997). These strategies were used by both partners and adult-children in the articles reviewed and are supported by the findings of recent research and reviews. For example, in their meta-synthesis, Wadham et al (2016) found that couples sought ways to continue to live life and hold distress at bay. Similarly, Walmsley and McCormack (2014) described family strategies to support continued family membership in people with advanced experience of dementia. They found that in some circumstances families were able to support communication and find ways of understanding the person with dementia. Conversely they also found that there were occasions when families appeared out of tune with the person with dementia and positioned them as diminished.

Furthermore, this synthesis brings together research which has included the person with dementia as an active participant, a voice which has previously largely been absent from such research (Ablitt et al. 2009). People with early experience of dementia demonstrated that they continued to actively work with others in their family to maintain their relationships; to make sense of the impact of dementia and to manage the changes that it brought. Consistent with previous research, the accounts of people with dementia demonstrated continued emotional awareness and awareness of the impact of dementia upon the family member involved in caring for them (Ablitt et al. 2010;

Burgener and Twigg 2002). Such insight and awareness facilitated opportunities for the relationship to continue to grow and for compromise and adjustment to take place, thus appearing to contribute to well-being and meaningful lives.

People with dementia contributed less to those themes where the experience of the impact of dementia upon the relationship was challenging. Where they contributed, their perspectives appeared to reflect positions of denial and resistance. This seemed to be as a consequence of a previously poor relationship; poor communication; being positioned by the other as a problem; or a lack of synchronicity in awareness and understanding, combined with the use of control by the family member involved in caregiving. Although this is less well developed in the synthesis and as such must be treated with caution, it has parallels with findings from Burgener and Twigg (2002) in highlighting that lower quality of relationship and caregiving relative stress predicted lower quality of life in the person living with dementia.

This synthesis largely reflected research considering couple relationships. The contributions from couples have significant parallels with the dynamics of dementia discussed by Keady and Nolan (2003) and the outcomes of recent systematic reviews of quantitative research (Ablitt et al. 2009; Quinn et al. 2009). In particular, this synthesis supports that, in the context of a previously positive relationship, effective adaptation to the impact of dementia involves emotional connectedness and open communication between the person with dementia and their spouse (Keady and Nolan 2003). Furthermore, 'working together' (Keady and Nolan, 2003) involves positioning dementia as the problem rather than the person. Thus couples appeared to engage in a complex process of 'holding' the dementia apart from the relationship while managing its impact on their day-to-day lives. One specific contribution of this synthesis is that it demonstrates the active participation of the person with dementia in this process.

The majority of the research studies focused upon the strengths and adaptive characteristics of couple relationships, with minimal material about negative impact, or about how past conflict influences current experiences. This may

reflect challenges in recruitment, as couples with a less positive relationship may be reluctant to participate and in the context of being interviewed together, may be less willing to discuss difficulties. However, it also seems possible that the desire to move away from an emphasis on burden and negativity may have resulted in less attention being given to those couples where such outcomes occur.

A lesser number of articles within this review address the experience of other family relationships. However the findings suggest that concepts such as commitment, quality of previous relationship and emotional connectedness are relevant across various relationships, as also found in previous qualitative research from the perspective of family caregivers (Piercy 2007).

Implications for research

This synthesis has highlighted possible directions for further research. Firstly, the more negative sub-themes (*disconnectedness, working apart and minimising*) occurred significantly less frequently in participants' accounts. Although small in number, the accounts that populated these themes were largely from research in which the person with dementia and their family member were interviewed separately. Additionally, the accounts were predominantly from the perspective of the family member, with significantly fewer quotations coming from a person living with dementia. Previous research has been criticised for its uni-dimensional focus on negative outcomes. However if negative and positive outcomes (Nolan et al. 2002), are not recognised by researchers, there is a risk of a shift to a similar uni-dimensional focus on positive experiences. Future research needs to give consideration to how to recruit and interview families, including the person with dementia, where relationships are less positive and to present a balanced view. To give freedom for expression of both positive and negative experiences it may be necessary to interview participants both together and apart, as well as to use methodologies which focus on live interactions between the family members involved in the research. It is also important to reflexively consider whether a desire to represent the impact of dementia in a

positive light results in a lesser focus on material which contradicts this desire.

Secondly, a limitation of current research is that the focus has largely been on couple relationships. Evidence from this synthesis and more recent research addressing family relationships suggests that intergenerational relationships including adult child-parent relationships are also affected by dementia. Furthermore, this synthesis has highlighted that family members across generations are actively engaged in a process of negotiation and renegotiation of roles and relationships. However, research has rarely considered how intergenerational family relationships manage and mediate the impact of dementia, in spite of evidence demonstrating that multiple generations are affected (Allen et al. 2009; Roach et al. 2014b; Garwick et al. 1994; Tolkacheva et al. 2011; Tremont et al. 2006). Further research is therefore required to provide an in-depth insight into the impact and management of dementia in a context of intergenerational family relationships.

Thirdly, existing research has largely focused upon people who have received a diagnosis of Alzheimer's disease, where the potential for maintaining the emotional relationship appeared to contribute to the positive relational experiences highlighted. However this has implications for less common forms of dementia. For example, behavioural variant frontotemporal dementia (bvFTD), involves changes in empathy, emotional warmth and understanding (Fernandez-Duque et al. 2010) and as a consequence, potential loss of an emotional relationship early in the experience of dementia. Further research studies are required to address possible differences in adjustment that arise from the psycho-social implications of these forms of dementia for family relationships.

Fourthly, many of the studies utilised a cross sectional design and many of the participants were early in their experience of dementia. Relationship quality and strategies to maintain the relationship have been shown to change over time, as the person finds it more difficult to engage in the conventions and strategies used previously to sustain relationships (Hellström et al. 2007; Nolan et al. 2002). As dementia has a progressive and

changing course, more longitudinal studies of its impact on relationships are required.

Finally, it is important to recognise that a significant limitation of current research is its focus on traditional family relationships. Family relationships are influenced by ethnicity, sexual orientation and divorce. Different family constellations and dimensions of difference remain an area for further research.

In light of the above conclusions, it seems that research exploring the reciprocal influence between dementia and family relationships is required. While a small number of studies exist in this area, there are a number of limitations to this research. These limitations include that they:

- Study specific cultures and are not necessarily directly transferrable to a UK based population
- Have not always included the perspective of the person with dementia, or indeed other, wider family members, despite evidence highlighting their active involvement in managing the impact of dementia upon their relationships
- Generally focus on families living with Alzheimer's disease. As indicated above, it would appear that less common forms of dementia may impact on relationships differentially thus specific studies in this area would be a valuable addition to the evidence base.

Accordingly, the next section considers the specific features of behavioural variant frontotemporal dementia, following which the experience of bvFTD is considered for the person with dementia and their families.

2.6 Behavioural Variant Frontotemporal Dementia

Frontotemporal dementia (FTD) is a particularly challenging and rare form of dementia, although it is the third most common form of young onset dementia (Harvey et al. 2003). FTD also occurs in older people (aged 65 and over) although with less frequency, however it remains underdiagnosed in this population (Warren et al. 2013; Baborie et al. 2012). Three subtypes of FTD occur, the most common of which is bvFTD which is caused by underlying

degenerative disease processes which specifically impact on frontal lobe functioning (Rascovsky et al. 2011; Warren et al. 2013; Gorno-Tempini et al. 2011). Warren et al. (2013) suggest that while the numbers of people with bvFTD are small, the disease is highly significant due to its wide ranging impact on the lives of those who experience it, in particular through changes in social cognition, aspects of cognitive function and behaviour (Warren et al. 2013). Each of these three areas is briefly outlined below.

Impact on Social Cognition

Social cognition involves the ability to understand the social world and apply this knowledge in everyday interactions with others. A number of aspects of social cognition are affected by bvFTD. These include:

- Theory of mind, involving the ability to;
    - Understand one's own and infer others beliefs, desires and knowledge,
    - take another's perspective and,
    - infer the emotions of others (Kipps and Hodges 2006; Fernandez-Duque et al. 2010; Sturm et al. 2011)
- Empathy, involving the ability to;
    - perceive another's emotional experience (affective component),
    - understand that experience (cognitive component) and,
    - take account of another's and one's own state in determining appropriate actions (Cuff et al. 2016; Lough et al. 2006).
- Unawareness of the emotional impact of bvFTD on oneself (Mendez and Shapira 2011)
- Emotional blunting, involving declining extraversion, loss of emotional warmth, unconcern or indifference to the experience of others (Bott et al. 2014; Joshi et al. 2014)

Impact on Cognitive Function

The frontal lobes govern many aspects of cognitive function involved in ensuring that it is possible to make sense of the external world and combine

this with internal states in order to engage in appropriate behaviour (ECDC 2011). The main areas of cognitive function affected include:

- Executive Function, which involves the ability to problem solve and plan ahead to decide on an appropriate course of action. This includes determining the sequence of steps needed to achieve a goal; initiating actions; monitoring actions and switching plans as needed. Finally, stopping actions when they are no longer required (ECDC 2011; Rascovsky et al. 2011)
- Impaired attention and concentration (distractibility) (Stopford et al. 2012).
- Changes in memory are contentious and are not included in the most recent diagnostic criteria for bvFTD (Bott et al. 2014; Rascovsky et al. 2011). However some suggest that deficits may be present as a result of impaired attention and others suggest that impaired anterograde memory is present in older people with bvFTD (Stopford et al. 2012; Baborie et al. 2012).
- Changes in insight and awareness, involving lesser or no awareness of deficits in multiple areas of functioning including language, executive function and activities of daily living (Massimo et al. 2013a; Salmon et al. 2008; Bott et al. 2014; Hutchings et al. 2015)
- Impairment in metacognition, involving awareness of own thought processes (Bott et al. 2014; Massimo et al. 2013a).

Impact on Behaviour

The impact upon social cognition and cognitive function described above combine together to affect the behaviour of the person with bvFTD. Changes in behaviour include:

- Knowing what is acceptable in social situations and conducting oneself appropriately (i.e. disinhibition; Hutchings et al. 2015; Bott et al. 2014; Warren et al. 2013).
- Apathy, involving distinct deficits in planning, initiation, motivation and self-care (Massimo et al. 2014).

- Impulsivity (Rascovsky et al. 2011).
- Perseverative, stereotyped or ritualistic behaviours (Rascovsky et al. 2011)
- Changes in eating habits, commonly involving preferences for sweet foods or fixations on particular types of food (Bott et al. 2014).

As a consequence of these changes, bvFTD is known to present particular difficulties for the person and their family (Merilees et al. 2013; Mioshi et al. 2013a; van Vliet et al. 2011; Ascher et al. 2010; Warren et al. 2013; Oyebode et al. 2013).

In addition to the symptoms described above, the point in the life cycle at which bvFTD occurs is significant. As it commonly affects younger people, there are psychosocial and practical implications associated with this life stage, including employment and financial consequences. Furthermore, young onset dementia may have relational consequences associated with having dependent children or caregiving responsibilities for parents. Wider family relationships and friendships are also likely to be affected (Roach, et al. 2014a; Allen et al. 2009; Svanberg et al. 2011; Oyebode et al. 2013). The next two sections therefore consider research which explores the experience of living with bvFTD for the person with the condition and their family members.

2.7 Search Strategy bvFTD and family relationships

A search was completed to identify the specific literature concerning family experiences of living with bvFTD in 2012 and then repeated in 2016 (table 2.5).

Table 2.5: Search strategy: frontotemporal dementia or frontal symptoms and family caregiving.
Keyword Search: Frontotemporal dementia OR Frontal Variant Frontotemporal dementia AND AND Family Caregiv* OR Caregiv* OR Family Functioning OR Carers OR Care* OR Identity OR Relationships OR Personal Experience
Databases searched: 1. Assia 2. Cinahl (EBSCO) 3. Web of Science

4. Ovid Search of BNI, Medline, Embase, Psychinfo, PsychARTICLES, CAB, Fulltext 5. Swetswise 6. IBSS 7. Pubmed 8. ISI
Inclusion Criteria: 1. No limits placed on disease stage 2. Any age of caregiver and any stage of caregiving as anticipated small number of studies 3. Methodologies including Cross Sectional or Longitudinal, RCT, Peer Review Studies 4. Limited to English Language 5. Published from 2010
Exclusion Criteria: Studies purely addressing Alzheimer's Disease or Dementia in the absence of focus upon frontal symptoms common in FTD
90 articles were retrieved. The articles obtained were subjected to review based upon the title and abstract. The full text of 27 articles was obtained. A further hand search of these articles and of other relevant journals identified a further 1 articles for inclusion.
A further search was repeated in July 2016, limited to dates between 2012 and current date 2386 abstracts were retrieved after duplicates were removed and subjected to a review of abstract and title. Of these 17 were selected and full text obtained. 2 further studies were identified from a hand search of references contained in articles and the journal Dementia.

The full text of 47 articles was reviewed and considered for inclusion in this literature review. Fifteen studies met the criteria for inclusion (Ascher et al. 2010; Avineri 2013; Brioschi Guevara et al. 2015; Chow et al. 2011; Diehl-Schmid et al. 2013; Griffin et al. 2015; Hsieh et al. 2013; Massimo et al. 2013; Mioshi et al. 2013a; Nichols et al. 2013; Oyebode et al. 2013; Roche et al. 2015; Wong et al. 2012a; Wong et al. 2012b; Wong et al. 2014). Given the limitations regarding thesis length, details of their methodologies, research questions and key results are summarised in appendix 4 (PDF CD). However, in the next two sections I present a narrative summary of their findings in relation to the experience of the person with bvFTD and the family experience of bvFTD.

2.8 The experience of living with bvFTD from the perspective of the person with the diagnosis

In the main and as noted earlier in this review, research on the subjective experience of living with dementia has largely focused on people living with the more common forms of dementia such as Alzheimer's disease. Where they have been included, the numbers of people with bvFTD are small and their experience has not been differentiated from that of people with more common forms of dementia. Griffin et al. (2015) suggest that researchers may have assumed that people with bvFTD lack insight and are therefore unable to reflect on their experience. However they contend that similar views used to be held about people with Alzheimer's disease, consequently it cannot be assumed that such research is impossible. Furthermore, the distinct differences in bvFTD warrant a specific focus.

While the search strategy described earlier (table 2.5) elicited articles considering the impact upon family caregivers, no studies considering the personal experience of bvFTD were identified from the database searches. A hand search of the journal Dementia identified one study and one further study which has some relevance to the personal experience of bvFTD was identified from a hand search of articles cited in recent studies. Both of these studies are qualitative and focus on one and five participants respectively (Avineri 2013; Griffin et al. 2015) and are therefore not generalisable. Nevertheless, they provide important insights and potential areas for further study. An assessment of the quality of these studies is contained in appendix 5.

In a single case study, Avineri (2013) demonstrated that a person living with bvFTD was able to recognise that while they may not have awareness of their difficulties, others around them might have a more accurate understanding. Conducting research using naturalistic rather than experimental conditions allowed the person with bvFTD to demonstrate aspects of insight and theory of mind, from which Avineri (2013) concluded that insight may be more appropriately represented as a continuum rather than entirely present or absent. Avineri (2013) also suggested that the participant actively sought to create a representation of her experience of

bvFTD and furthermore that this was influenced by the interactional environment of the study in which the participant's daughter and a doctor were present.

Griffin et al. (2015) undertook a qualitative study, exploring the perspectives of five people living with bvFTD using Interpretive Phenomenological Analysis. Four of the five people were interviewed alone and one with a spouse. Two superordinate themes were identified, *Bewilderment* and *Relationships with others*. Griffin et al. (2015) found that while participants were often able to report changes, they appeared to have difficulty in emotionally appreciating the impact and effect of the changes on themselves. The diagnosis, a reduction in abilities and restrictions on activities they had previously engaged in negatively impacted upon their sense of self. This was particularly because they did not necessarily accept the legitimacy of the restrictions and struggled with the loss of control associated with changes such as loss of employment and driving. In the second superordinate theme, it appeared that the disparity between theirs and others' understanding continued. Participants appeared to struggle to appreciate that others might be affected by their difficulties and in the context of threats posed to self by others' perspectives, chose to avoid or blame others for their actions.

These two studies appear to suggest firstly, that people with bvFTD are able to actively participate in research of this kind, although as Griffin et al. (2015) highlight, modifications to interview style may be necessary in order to maximise opportunities for participation. Similarly, Avineri (2013) points to the interactional environment of their research which may have supported the person with bvFTD to provide a more detailed perspective. Secondly, both studies highlight that awareness and insight are complex and nuanced experiences. In particular, Griffin et al. (2015) suggest that while cognitive awareness may be present, emotional appreciation of changes may not be. Consequently, this has implications for sense of self when interpreting the reactions of others as well as social behaviour. Further research studies are required to further elucidate the personal experience of bvFTD. As Avineri (2013) suggests, undertaking such research in naturalistic environments seems more likely to achieve the depth of understanding needed.

Additionally, these studies imply that a fruitful area for further research and intervention development could be to consider ways in which self-concept can be supported within a familial and social context.

2.9 Family experiences of Frontotemporal Dementia

Thirteen articles were located for review from the search strategy described above (table 2.5). Of the studies that were selected, three utilised qualitative methodologies, involving focus groups, (Nichols et al. 2013) and Interpretive Phenomenological Analysis (Massimo et al. 2013b; Oyebode et al. 2013). Of the ten articles using quantitative methodologies, one used descriptive statistics (Chow et al 2011) and one used a text analysis methodology (Ascher et al. 2010). The remainder used correlational research designs.

The ten quantitative studies were assessed for their quality according to the guidelines for critiquing quantitative research developed by Coughlan et al (2007) in table 2.6 below. Studies were assessed against the questions asked about each of these elements and assessed as meeting (y) partially meeting (p) or not meeting (n) each. Quantitative studies were highly variable in quality. The three qualitative articles were assessed according to the criteria described earlier (table 2.2). These studies largely met the criteria for assessment of qualitative research fully. The full results of the assessment are contained in appendix 5 (PDF CD).

Table 2.6 Guidelines for critiquing a quantitative research study Coughlan et al. 2007: 659
Elements influencing the believability of the research
1. Writing style
2. Author
3. Report title
4. Abstract
Elements influencing the robustness of the research
1. Purpose/ research problem
2. Logical consistency
3. Literature review
4. Theoretical framework
5. Aims/ objectives/ research question/ hypothesis
6. Sample
7. Ethical considerations
8. Operational definitions
9. Methodology

10. Data analysis/ results
11. Discussion
12. References

Of the thirteen studies, five contributed to aspects of the family experience of living with bvFTD, which included the impact on their relationships. Seven studies were concerned with the impact of bvFTD on family members who were primarily involved in caregiving for the person with bvFTD and their coping styles; and one study considered both. The results of these studies are therefore presented in two sections.

The family experience of bvFTD

Six studies contributed to understanding family members' experiences of bvFTD (Ascher et al. 2010; Chow et al. 2011; Diehl-Schmid et al. 2013; Massimo et al. 2013b; Nichols et al. 2013; Oyebode et al. 2013). Participants included spouses, siblings, children and young people and adult children. Five of the six studies did not involve the person living with bvFTD. Two of the three quantitative studies sought to identify the overall needs of family caregivers of people living with bvFTD (Chow et al. 2011; Diehl-Schmid et al. 2013) and their approach is complemented by the three studies using qualitative methods, which assist in the development of an in-depth understanding of family members' experiences of living with bvFTD (Massimo et al. 2013b; Nichols et al. 2013; Oyebode et al. 2013).

Changes in identity of the person with bvFTD were described in all three of the qualitative studies, with a common theme of 'not the same person' emerging. The emotional impact of these changes was evident, with all three studies identifying the experience of loss associated with this change. These changes impacted upon the nature of the relationship, with participants describing the loss of emotional connectedness, shared communication and affection (Massimo et al. 2013b; Nichols et al. 2013; Oyebode et al. 2013). Additionally, in one study, spouses described changes in sexual intimacy (Oyebode et al. 2013). Nichols et al. (2013) also referred to changes in relationship with other family members, including the 'well' parents which were consistent with the perspectives of young people described earlier in this review.

Family members in all three studies also described changes to self, involving becoming a caregiver and taking on increased responsibility for the person with bvFTD. Furthermore in two of the studies some participants appeared to feel that their lives and their hoped for future had been irreparably damaged (Oyebode et al. 2013; Massimo et al. 2013b).

Five of the studies (Chow et al. 2011; Diehl-Schmid et al. 2013; Massimo et al. 2013b; Nichols et al. 2013; Oyebode et al. 2013) described changes in behaviour as being challenging. Such changes included; loss of insight and awareness, loss of empathy, aggression, changes in personality, social behaviour, judgement and risk taking and loss of inhibition. Diehl-Schmid et al. (2013) highlighted that difficult behaviours were associated with outcomes such as increases in depressive symptoms in family caregivers. Four studies highlighted that family members had developed strategies to cope with these difficulties and had developed self-efficacy as a consequence (Chow et al. 2011; Massimo et al. 2013b; Nichols et al. 2013; Oyebode et al. 2013). Three studies provided detailed examples including promoting the quality of life of the person with bvFTD, developing skills in new areas, learning about bvFTD and finding ways to maintain aspects of the relationship (Massimo et al. 2013b; Nichols et al. 2013; Oyebode et al. 2013). Participants also highlighted the importance of understanding bvFTD in order to reframe the behaviour of the person and find ways of maintaining some connectedness.

A gap in existing evidence was that of the impact of bvFTD on relationships which includes the perspective of the person living with dementia. Ascher et al. (2010) found that bvFTD has a significant impact on the relationship between couples, including lower relationship satisfaction. They recommended that further research is needed involving people living with bvFTD and those that care for them (Ascher et al. 2010).

Impact of caregiving on family members caring for a person with bvFTD and their coping styles

Eight studies considered the impact of caregiving for a person with bvFTD on the wellbeing of the caregiver and their coping styles (Brioschi Guevara et al. 2015; Diehl-Schmid et al. 2013; Hsieh et al. 2013; Mioshi et al. 2013a; Roche

et al. 2015; Wong et al. 2012a; 2012b; 2014). Two of the studies drew results from the same cohort, although reporting findings concerning two separate but linked research questions (Wong et al. 2012b; Wong et al. 2014). In the majority of studies the participants were female and spouse caregivers. All of the studies used a cross-sectional design and the majority used validated tools.

Some studies sought to isolate individual symptoms of bvFTD associated with relational functioning and in particular changes in theory of mind and empathy and explore their relationship to caregiver outcomes. One study found that loss of empathy was associated with a perceived lack of care (Hsieh et al. 2013). Another found that loss of theory of mind was positively associated with caregiver burden (Brioschi Guevara et al. 2015). There are however, conflicting results concerning the relationship between caregiver burden and lack of care in the relationship (Hsieh et al. 2013; Mioshi et al. 2013a). Furthermore, some studies suggest that it is likely that multiple factors acting in combination are responsible for outcomes, for example Diehl-Schmid et al. (2013) found in their survey, that caregivers experienced changes in personality, the need for care and supervision as most burdensome. Consistent with their findings, Mioshi et al. (2013a) found that it was the experience of behavioural changes when combined with disease severity that was the main predictor of caregiver burden.

Some of the studies sought to compare caregiving for different types of FTD and other forms of dementia. Mioshi et al (2013a) found that family caregivers of people with bvFTD were significantly more burdened and depressed than those caring for people with other FTD subtypes or Alzheimer's disease. Similarly, Hsieh et al. (2013) did not observe any significant associations concerning empathy loss and carer variables in Alzheimer's disease. They suggested that these symptoms appear later in the course of Alzheimer's disease, in contrast to bvFTD where early changes in these functions are apparent. Wong et al (2012a) found that caregivers of people with bvFTD experienced significantly more strain, distress, depression and had less perceived control than caregivers of people with Alzheimer's

disease. Thus it would appear from these studies that bvFTD may create specific and significant challenges for family members in caregiving roles.

Finally, two of the studies explored the role of coping strategies in mediating outcomes for family caregivers (Roche et al. 2015; Wong and Wallhagen, 2014). Roche et al (2015) considered the role that emotion-focused, problem-focused and dysfunctional coping had in mediating the experience of depression and quality of life for caregivers of people with bvFTD. They found that caregiver strain was common and that problem focused and emotion focused coping did not alleviate strain. Furthermore, dysfunctional coping when combined with low financial resources and the need for high levels of care was found to increase strain. However they also found that coping could mediate the effect of strain, for example problem focused coping alongside a younger age of caregiver was found to be most beneficial, reducing the effect of strain on quality of life. Conversely, emotion-focused coping was not found to provide a mediating effect between strain and depression or quality of life. The findings of Wong and Wallhagen (2014) contrasted with these findings. They also considered these three types of coping and found that emotion focused coping was associated with mental health issues and problem-focused coping was associated with physical health issues. Furthermore they found a significant association between coping style and gender, with women more likely to use emotion-focused coping. It remains clear that further research is needed to identify which coping strategies are likely to be most effective for family caregivers of people with bvFTD.

These studies have some methodological limitations. Sample sizes in many of the studies are small, resulting in difficulties with identifying differences between types of caregiving relationships, gender effects, subtypes of FTD, being able to control for length of time caring and achieving statistical rigour. Many participants were recruited from caregiver support groups or were already in contact with services and may therefore be considered ‘help-seekers’ or be people who have significant need for assistance (Roche et al. 2015). Consequently the results of these studies need to be interpreted with caution and cannot necessarily be generalised.

Furthermore, some of the studies acknowledge the difficulties associated with quantitative research in this field (e.g. Mioshi et al. 2013a; Hsieh et al. 2013; Diehl-Schmid et al. 2013). The challenge of research of this nature is the complexity of relational functioning and the difficulty of isolating individual components against a specific dependent variable. Indeed, variables may be operating both separately and together within a relational context but some of the research is only able to show linear associations between independent and dependent variables. Furthermore, as Hsieh et al. (2013) suggest, conducting research into discreet symptoms such as empathy based on standardised questionnaires may not facilitate an in-depth understanding of the nuanced way in which changes occur or how these are experienced. Thus, as described earlier, Hsieh et al (2013) suggests that observation in natural environments is required to strengthen such research.

Summary

BvFTD brings unique challenges associated with the nature of the symptoms and their impact upon relational functioning, behaviour and activities of everyday life. Current research considering the experience of bvFTD for the person and their family and its impact upon their wellbeing is still in its infancy. Qualitative studies are emerging which although not generalisable; provide opportunities to deepen understanding of the similarities and differences associated with bvFTD. Two studies demonstrate that it is possible for people with bvFTD to share their perspectives and to participate in research. They also indicate that while people with bvFTD may have difficulties with awareness and insight these are not all or nothing concepts consequently, it is possible for them to be aware of the changes in relationships that may be occurring. Studies considering family experience highlight early changes in relationship quality and associated distress. Furthermore, they emphasise that family members experience significant changes in roles and identity as a consequence of the impact of bvFTD. Although these experiences also appear in studies considering other forms of dementia, it seems that they occur at an earlier point in the course of bvFTD and when combined with the significant changes in behaviour, create particular challenges for family members.

Quantitative studies have fundamental challenges with sampling and recruitment due to the relative rarity of bvFTD in comparison with other more common forms of dementia. Furthermore, it would seem that a simple application of concepts from existing caregiving research, such as burden, is problematic. Research is beginning to acknowledge the multiplicity of factors that may influence the outcomes associated with caregiving in the context of bvFTD, but needs to achieve greater sample sizes. Additionally, matching of family caregivers and persons with bvFTD is needed in regard to length of time experiencing dementia, gender and relationship type in order to advance understanding. Nevertheless, it would seem that there are areas of significance, which while requiring further study, are important. These include the higher levels of depression, strain and burden evident when caregiving for a person with bvFTD when compared with caregiving in other forms of dementia. Furthermore, that it is the combination of behavioural changes and disease severity that predicts poor outcomes. Finally, problem-focused and emotion-focused coping are important areas for further study when considering how family caregivers cope with bvFTD.

2.10 Conclusion

Research is still limited in studying bvFTD, its impact and the experience of living with it and it is clear that further research is required. The results of the small number of bvFTD studies reviewed above have parallels with the findings of the synthesis and the research described earlier. They reinforce the need for a focus on family relationships, as these studies highlighted that a range of family members including the person with dementia are affected. However this research also highlights differences, not least of which is the specific and direct impact upon relational functioning at an early point in the experience of bvFTD. As Ascher et al. (2010) suggest it seems possible that people with Alzheimer's disease can work together with their family to maintain relationships in the early experience of the illness. However in bvFTD, such relational work is fundamentally affected by changes in empathy, awareness, theory of mind and reciprocity. Attributes such as reciprocity and empathy are important in healthy relationships (Cox, 2009) and research which considers the reciprocal relationship between bvFTD and

family relationships, which includes the person living with dementia, would therefore seem to be necessary.

2.11 Rationale and objectives for this study

In light of the above, the primary objectives of this research study are to:

- Develop an in-depth and detailed understanding of the inter-generational family experience of bvFTD over time. Considering in particular the emotional experience, impact upon relationships and the strategies that families use to make sense of and cope with the impact of the changes associated with bvFTD such as loss of empathy and theory of mind.

- Furthermore, to use the results of this research to inform the development of interventions which seek to enable families to live well with bvFTD.

The following research questions were formed from these objectives:

1. How were family relationships experienced prior to bvFTD occurring (considering processes of reciprocity, cohesion, collaboration, communication, conflict, allegiances, roles and responsibilities)?

2. How have families made sense of and understood the changes associated with bvFTD beginning with the early signs before diagnosis and continuing throughout their involvement in the research?

3. What are the implications of this process of sense making for coping with the experience of bvFTD within a relational context over time (considering the verbal, embodied and emotional aspects of coping)?

4. How has bvFTD affected and impacted upon family relationships over time (considering processes of reciprocity, cohesion, collaboration, communication, conflict, allegiances, roles and responsibilities)?

5. What are the reciprocal influences between family relationships and coping processes in the context of bvFTD?

6. What does this tell us about the facilitators and barriers to living well with bvFTD and what interventions might be needed in order to support families to live well with bvFTD?

Chapter 3: Methodological Approach

3.1 Introduction

In order to answer the research questions identified at the end of Chapter 2 and achieve an in-depth and longitudinal understanding of the experiences of families living with bvFTD, I chose to utilise a qualitative research design. It is suggested that qualitative research:

> *"Involves the studied use and collection of a variety of empirical materials… that describe routine and problematic moments and meanings in individuals' lives. Accordingly, qualitative researchers deploy a wide range of interpretive practices, hoping always to get a better understanding of the subject matter at hand". (Denzin and Lincoln 2003: 5)*

Thus a qualitative design is well suited to achieving answers to the research questions raised by the review of the literature and my professional experience. Furthermore, as identified in the literature review, the methodological limitations and challenges associated with existing research supports this decision. In particular, research has commonly focused on discreet aspects of bvFTD without recognising the multiple factors that are likely to act together to influence the experience of bvFTD for people living with the diagnosis and their family.

Furthermore, research which seeks to understand the perspectives of people living with bvFTD and the nuanced nature of their experience seems most likely to be gained from inquiry that is conducted in their natural environment (Griffin et al. 2015; Hsieh et al. 2013; Avineri 2013). Although it must be acknowledged that the presence of a researcher will influence that 'natural' environment. Additionally, qualitative research can be flexible and responsive to the particular challenges faced as a consequence of dementia (Nygard, 2006; Hellström, et al. 2007b; Pesonen, et al. 2011). I chose to employ a pluralistic research design involving narrative analysis and grounded theory within a constructivist paradigm. This chapter reviews the ontological and epistemological position informing the research design and provides a rationale for the methodological approach.

3.2 Methodological approaches in qualitative research

Qualitative and quantitative research is underpinned by theoretical paradigms that are described as:

> *"The basic belief system or worldview that guides the investigator, not only in the choices of method but in ontologically and epistemologically fundamental ways" (Guba and Lincoln 1994: 105).*

These authors identify four paradigms which have specific ontological positions (Table 3.1):

Table 3.1 Four paradigms of research (Guba and Lincoln 1994)

Paradigm	**Ontological Position**
Positivism	Naïve realism: Within this position, it is suggested that a measurable 'reality' exists that can be directly measured
Post-positivism	Critical realism: Within this position, reality is thought to exist but measurement is suggested to be flawed due to the limitations of the world in which we exist and the fallibility of human intellect
Critical theory	Historical realism: Within this position it is suggested that a reality exists which has been shaped over time by social, political, cultural, economic, ethnic and gender factors such that it has formed into specific constructions which are open to measurement
Constructivism	Relativism: within this position, it is suggested that multiple realities exist, which are fluid and open to change as they are grounded in individual and cultural experiences

Each of these ontological positions is informed by an epistemology which articulates the means through which knowledge is constructed. Each position is associated with specific methodologies as described in table 3.2:

Table 3.2: Epistemological positions and their associated methodologies Guba and Lincoln 1994 (109-111)

Ontology	Epistemology	Methodology
Positivism	*Dualist/ Objectivist* Findings are 'true' Experimenter is independent of concept being studied. It is possible to control for 'threats' to validity.	*Experimental research* hypotheses are proposed and tested. Generally uses quantitative methods

Post-positivism	*Objectivist position*. Emphasis on key tenants of objectivity including 'fit' with prior knowledge and views of peers Findings are probably true.	*Modified experimental/ manipulative.* Seeks to disprove hypotheses. Inquiry occurs in natural settings. Acceptance of need to gain 'insider knowledge' so also associated with qualitative inquiry, specifically Glaser's approach to Grounded theory.
Critical Theory	*Transactional and subjectivist position* recognises that the researcher and the focus of inquiry are linked. Researcher influences the inquiry. Findings are influenced by the researcher's values and beliefs, i.e. knowledge is influenced by values and implicitly defined by those values.	*Dialogic and Dialectical.* Methodology involves interaction between researcher and focus of inquiry to achieve a consensus, which could be perceived as a 'truth'. Methodologies seek to achieve a critical understanding of factors influencing the experience, such as discrimination. Associated with action research or transformative research. Also ideology critique. Empowerment is viewed as an important outcome
Constructivism	*Transactional and Subjectivist position.* As with critical theory, assumes a link between researcher and participants. The findings of inquiry are co-constructed.	*Hermeneutical and dialectical* Methodologies generate findings through interactions between researcher and participants. Results achieve an outcome that is more informed, however not a 'truth'. Belief in multiple realities that develop and change over time as new experiences emerge. Associated methodologies include Grounded theory (Corbin and Strauss 2008, Charmaz 2006) and Narrative Analysis (Riessman 2008).

In considering which paradigm I aligned myself to and therefore which approach I should take to this research, I considered my personal and professional values and experiences alongside the arguments I have already made earlier in this chapter for adopting a qualitative approach to the study. The limitations of existing positivist research in this area led me to discount this paradigm. Similarly, I struggled with the perception inherent within post-positivism, that there exists an unassailable truth that can be uncovered, even if only partially. Furthermore, it seemed to me that the researcher's values and beliefs cannot be contained in such a way that they do not influence the research.

Additionally, as a mature professional in midlife, I have been regularly confronted with different realities, in working with families living with dementia and in my personal life. Equally, in my work I have been regularly reminded of the way in which my values and beliefs and those of the service within which I operate, influence the way in which families living with dementia are constructed. For example, when I commenced nursing in 1979, people with dementia were constructed within a biomedical paradigm. The predominant 'reality' was that people with dementia were perceived as less than human and in this context; care was reductionist and focused on meeting physical needs. Care was not about communicating because it was assumed that '*they wouldn't understand*'. I experienced many moments which challenged this view, where people's essential humanity and experience of the world shone through in their efforts to make themselves heard. It appeared to me that their reality and my own seemed very different from that of some of the professionals that I worked with. In the early 1990's the advent of person centred care (Kitwood 1997) challenged this dominant narrative. Consequently, my world view broadened over that time period as did my understanding of what it meant to be a nurse working with people who lived with dementia. Similarly my experience of families, as referred to in chapter 1, underwent a comparable process.

Consequently, I explored whether critical theory or constructivism should inform my research. It could be argued that critical theory has considerable relevance to the experience of families living with bvFTD. Indeed it may be appropriate to consider the historical, institutional, cultural and discriminatory practices that influence the family experience of bvFTD. However in considering the experiences that had brought me to this research, I was increasingly uncomfortable with the idea that there was a single insight to be uncovered. The nature of working with families illustrates as Jessop (1981) identifies:

> *"There may well be as many valid realities as there are interacting individuals, with no reason to consider one version more authoritative than another" (Jessop 1981: 102)*

Although it is possible that this research could be transformative, I was concerned with providing a space for the multiple perspectives of families in this context to be heard, albeit that this would inevitably be my interpretation of that experience. Consequently, in light of the above, I chose a constructivist paradigm to inform my approach.

However, this does not mean that I ascribe to the position of ontological relativism. Unlike Guba and Lincoln (1994), Willig (2016) suggests that it is important to see ontology and epistemology in constructivism as separate although linked. She proposes that adopting realist ontology does not automatically mean a commitment to an unassailable 'truth'. Corbin (Corbin and Strauss 2008) also raises this, indicating that while she believes there is no single reality to be discovered, she does believe that there are external events which occur. She further articulates that:

> *"It is not the event itself that is the issue in our studies, because each person experiences and gives meaning to events in light of his or her own biographies or experiences" (10).*

Therefore, Corbin (Corbin and Strauss 2008) and Willig (2016) suggest that constructivist research seeks to uncover the meanings and multiple realities that individuals might give to events. These are then constructed by researchers into narratives, concepts or theories which assist us to make sense of these multiple realities. Willig (2016) therefore proposes that qualitative research is often based upon a combination of ontological critical realism and epistemological relativism. She provides the example of AIDS suggesting that as a condition, it exists although it is also socially constructed. I have adopted a position in this research which is consistent with her perspective. I believe that bvFTD as a condition exists (although I accept that this may be challenged by others). However, in undertaking this research, I have sought to uncover the way in which families and individuals within families make sense of and construct bvFTD. I have therefore elicited multiple and sometimes conflicting realities within and between families concerning the meaning of bvFTD and the actions these actors engage in to manage their 'reality' of living with bvFTD.

Finally, within the constructivist paradigm, there is an open acknowledgement that the products of such research are constructed in a dialogue between researcher and participant. Consequently the values and beliefs of researchers are unavoidably central to the way in which the findings are created and constructed. Guba and Lincoln (1994) suggest that to exclude the researchers' values from the products of this research would be inexcusable. Therefore reflexivity of the researcher is a central component of the process of constructivist research. In this study, I have used reflexivity and reflection to consider my influence on the research at all stages. Discussion of this occurred in Chapter 1 and is explored further in Chapters 4, 6 and 10, where I consider my influence on the research process and outcomes.

3.3 Methodology

In selecting a methodology, I discounted phenomenological methodologies such as Interpretative Phenomenological Analysis as they are largely concerned with individual lived experience and seek to understand the person's internal world (Shinebourne 2011). As the aim of the research was to uncover the reciprocal influences between family relationships and bvFTD, the focus of study was largely exploring the meaning created between individuals. Consequently methodologies which were influenced by theoretical positions involving human action and interaction were best suited to this study. Possibilities included:

- Constructivist Grounded Theory (Charmaz 2006, Corbin and Strauss 2008)
- Narrative Analysis (Riessman 1993, 2008)
- Ethnography (Chicago school approach, Deegan 2001)

I was already familiar with ethnography, having carried out a research study exploring the experience of grandchildren and grandparents when the grandparent had dementia. Its benefits include that it is particularly suitable for studying groups who are hard to reach and for understanding the often hidden meanings and assumptions informing everyday life (Harper and La Fontaine 2009). However there are also challenges to implementing an

ethnographic approach. It is time consuming and usually involves long periods of time in the field of study (Murphy 2005; Lüders 2004). Ethnography's main approach to data collection is participant observation and this is frequently carried out in workplace, community or institutional settings, such as Goffman's study in psychiatric hospitals (Goffman 1961). While participant observation would provide an opportunity to study 'life as it is lived' (Hammersley and Atkinson 1963), I was concerned that conducting observations in a person's private home would be difficult without significantly impacting upon the 'natural environment'. Furthermore, from my experience of the previous research study, maintaining a detailed fieldwork journal in such circumstances is very difficult due to the nature of the setting. Consequently this methodology was discounted.

Both Narrative Analysis and Grounded Theory had characteristics which were suited to the research questions I had identified and each of these methodologies is now considered in turn.

Narrative Analysis

Esin (2011) defines narratives as stories with *"a clear sequential order, that connect events in a meaningful way for a definite audience… Narratives are powerful forms of giving meaning to experience" (93)*

Narrative analysis (NA) is therefore a process that can assist us to understand the intricacies of human lives and relationships (Esin 2011). NA draws from constructivist and naturalist epistemological positions; the latter being described as suggesting that narratives are a direct representation of the reality of an individual and are concerned with what their experience is. Alternatively, constructivist NA is suggested to be concerned with *how* social order is created through talk and interaction. Consequently, it is particularly useful for considering *how* identity is constructed within certain contexts such as the family. She further suggests that constructivist NA is concerned with *how* people make sense of their experiences (Esin 2011).

Riessman (2008) suggests that NA is a family of analytical approaches that interpret oral, written and visual narratives. The focus of NA is the 'narrative', the 'story' created to provide meaning to experiences and events (Esin 2011;

Lal et al 2012). Narratives are therefore used to communicate our experience of the world. They are co-constructed, assist in creating reality between the narrator and the wider world and are influenced by the world in which the narrator exists (Esin 2011). Generally, NA involves case centred research, although what is considered to be a 'case' can range from individuals to communities (Riessman 2008). Narrative methods have a long history of use in studies concerning health and ill health (Frank 1995; Riessman 1993) and are particularly useful in "*examining the ways in which an individual's self-identity is challenged and changed through the impact of traumatic life-events, such as being diagnosed with a chronic or terminal illness"* (Thomas et al. 2009: 789). Bingley et al. (2008) suggest that storytelling (i.e. the construction of narratives) is often a fundamental part of making sense of disruptions to our everyday lives, such as ill-health or disability.

Four different versions of narrative analysis have been described, including, thematic, structural, dialogic or visual. Although more than one approach may be used (Riessman 2008) and each may subsume multiple methods of analysis. Indeed Mishler (1995) proposes that there is no single way to analyse texts. It is nonetheless the case that NA seeks to preserve the 'whole' of the narrative text, rather than thematically fragment it (Riessman 2008). Nevertheless Riessman (2008) suggests that NA can generate categories from which theoretical interpretations can be made. NA is thought to facilitate opportunities to uncover multiple realities which may be complementary or divergent (Esin 2011).

Grounded Theory

Grounded theory (GT) emerged from the work of two sociologists, Glaser and Strauss (1967), although subsequently, they took divergent paths in their development of the methodology (Nolas 2011). It was developed as a consequence of the many criticisms of qualitative research such as a lack of a systematic approach. A number of forms of GT have arisen from the original methodology including Constructivist GT methodology and Straussian GT (Charmaz 2006; Corbin and Strauss 2008). The main proponent of constructivist GT is Charmaz (2006).

Grounded theory arose from symbolic interactionism which suggests that "*people construct selves, society and reality through interaction"* (Charmaz 2006: 189). As a consequence, GT is focused upon studying social and psychological processes, actions, interactions and structures (Charmaz 2006; Burck 2005). GT also has a history of use in studies concerning health and ill health and is useful for learning about areas that are less well understood (Burck 2005).

Charmaz (2006) suggests that constructivist GT involves a set of principles and practice rather than prescriptive methods. Nevertheless, there are core practices involved in the process of all methods of GT (Table 3.3):

Table 3.3: Core practices associated with Grounded Theory (Nolas 2011; Charmaz 2006)	
Constant comparison	involving the generation of codes and categories through a process of comparison within and between different sets of data to advance conceptual understanding
Abductive inference	considering all possible explanations for the data, forming ideas about the data and then subjecting these ideas to rigorous scrutiny empirically and by returning to the data to identify the most likely explanation
Reflexivity	the researcher intrinsically influences the process and outputs of GT and must therefore account for the decisions they make and the influence they have on the production of the research, the way in which they relate to participants and how they represent participants in the report

Within the context of these practices, Charmaz (2006) indicates that constructivist GT involves an interpretation of *how* and sometimes *why* participants construct meanings and act in particular ways. Data collection methods are flexible and can involve participant observation and interviewing (Nolas 2011). Data is fragmented in order to develop analysis, but ultimately brought back together to form a coherent story (Charmaz 2006). The ultimate goal is the production of substantive theory, although it is acknowledged that some do such research without intending to produce a theory (Charmaz 2006; Corbin and Strauss 2008). Finally, within constructivist GT, it is acknowledged that the products of such research are influenced by and dependent upon the researcher's view and thus can only be partial representations of the realities of participants (Charmaz 2006).

3.4 Rationale for the chosen methodologies

I recognised that both of these methodologies had advantages when considering the nature of the research I sought to undertake and during the process of refining and developing my approach, I vacillated between the two. I was drawn towards NA because it offered the opportunity to use flexible research methods. I wanted where possible to involve all family members who wished to take part, yet there are known difficulties in using more structured methods of data collection with people experiencing cognitive challenges (van Baalen et al. 2010). Furthermore, bvFTD impacts upon the whole family and presents significant challenges to family as well as individual identity. As described above, narrative methods are believed to be particularly relevant as a method of gaining insights into the ways in which identity is constructed. However, it seemed that GT also allowed for such flexibility. Furthermore, although Reissman (1993) suggests that NA can facilitate research exploring psychological and social processes, GT is particularly positioned to do this given its focus upon actions and interactions (Charmaz 2006).

After consideration of the early and emerging data from the interviews I moved from using one methodology to using a pluralistic approach. Frost (2009) suggests that combining methodologies facilitates opportunities to achieve the '*richest experience possible*' (11) and to provide multiple perspectives on the same issue (e.g. Burck 2005). Furthermore, Lal et al. (2012) suggest that as long as the ontological and epistemological positions adopted are commensurable then combining GT and NA is possible. Therefore I chose to use narrative analysis to guide my analysis of family relationships (research questions 1 and 4) and grounded theory to guide my analysis of the psychosocial coping processes used by families to make sense of and manage the impact of bvFTD (research questions 2 and 3). The results of these analyses were brought together to answer questions 5 and 6.

Furthermore consistent with the views of Riessman (1993) and Charmaz (2006), I recognised that constructivism proposes that our reality is constantly being reworked and revised. Therefore, as discussed in Chapter 2, it seems likely that the meanings and realities of families living with bvFTD will change

over time, particularly as bvFTD is a progressive and unpredictable condition. Accordingly I chose to undertake a qualitative longitudinal design as a means of capturing the temporal nature of this experience.

3.5 Conclusion

In seeking to address the aims of the research as identified at the end of Chapter 2 and in light of the challenges existing in the current literature, I chose to undertake a qualitative inquiry with a longitudinal design. Having reviewed the ontological and epistemological paradigms influencing qualitative research, I chose to align my approach within the constructivist paradigm. This recognises that we do not have direct access to a single 'truth' but that multiple realities exist and are subject to change and reconstruction over time. While placing my research within epistemological relativism, I chose to align myself with ontological critical realism.

I reviewed the methodologies associated with constructivism that are particularly suited to addressing the research aims. Although initially adopting a single methodology, after considering the data emerging from early interviews, I chose to use a pluralistic approach, involving grounded theory and narrative analysis as the methodologies informing my study.

The next chapter considers the way in which these methodologies were operationalised within this research study, including describing the research participants, the way in which data was obtained, analytical methods and reflexivity.

Chapter 4: Methods

4.1 Introduction

In this chapter I describe the overarching research design and the processes used to address the research aims including ethical approval, recruitment, data collection and analysis.

4.2 Overarching research design

As described in the previous chapter, a qualitative, pluralistic longitudinal design was planned, using grounded theory and narrative analysis. The methods associated with each of these methodologies are now described, following which the research design is outlined.

Narrative Analysis (NA)

As briefly mentioned in Chapter 3, a range of methods of analysis can be used in NA. Each of these is described in table 4.1:

Table 4.1 Forms of Narrative Analysis (Riessman 2008)	
Thematic Narrative Analysis	Exclusively concerned with the content of the narrative, rarely includes how, to whom or for what purpose. The story is kept intact by theorizing from the case. Prior theory can be used to inform interpretation. Often pays attention to societal context, but not necessarily to the context in which the narrative was generated.
Structural analysis	Concerned with content, but attends to the form, how a narrative is told. Data reduction is employed thus narratives are 'ordered' in particular ways, for example using Labov's (1972) elements: abstract, orientation, complicating action, evaluation and resolution. Rarely pays attention to societal context.
Dialogic / Performance analysis	Makes selective use of previous two forms as well as considering how narratives are produced and enacted between speakers. It considers who the story is for, when and why it is said. The researcher has an active presence in the text. Focus in detail on a single narrative. Pays attention to local and societal context.
Visual analysis	Makes use of all three of the previous forms of analysis, but explores visual representations of narrative as well as textual. Seeks to critically consider how identities are composed and performed visually (Riessman 2008: 179).

While separating these methods for the purposes of writing about them, Riessman (2008) invites researchers to consider what best fits their research, suggesting that it is possible and appropriate to use a combination of approaches. Nonetheless, whichever approach is used, Riessman (1993) suggests that the representation and organisation of these stories in research should acknowledge that we cannot directly 'give voice' to these narratives, rather that there are "*layers of representation of experience*" (8). She suggests that the stories that we tell about others' experiences and their narratives are always partial representations. As such, we cannot have direct and unambiguous access to the meanings of others. As researchers, we make choices about which aspects of a narrative we focus upon and give prominence to. There is no set of strict guidelines as to how NA should be undertaken (Mishler 1995; Esin 2011). Rather, it is suggested that researchers are required to interpret the methodology and creatively apply it to their specific research context (Esin 2011).

In the current study, I chose to focus upon what was being said and collaboratively constructed within an interactional context. I considered how the narrative illuminated the ways in which families constructed their relationships with other family members and the meanings they held about these relationships. I also considered how the narratives were communicated.

I was also conscious that narrative analysis frequently focuses on small numbers of narratives, whereas I intended to collect a corpus of data that involved interviews with a range of family members over time. Consequently I needed to consider methods that would allow for the analytical approach to be manageable. I therefore chose to undertake Narrative thematic analysis, as this method has some parallels with Grounded Theory (GT) methodology (Riessman 2008; Ross and Green 2011) and would facilitate a complementary approach to data. In adopting this analytical method, I also considered Riessman's (2008) description of the limitations of this approach. She suggested that the researcher's role in the construction of the narrative is often absent, that assumptions may be made across 'cases' about the universality of a particular meaning and that local contextual characteristics

are often not addressed. Therefore in adopting a constructivist approach, I recognised the need to ensure that my presence in the research was evident and that I paid attention to the diversity of meanings across families and individuals within families. Finally I also acknowledged the importance of taking account of the context in which the narratives are produced.

Grounded Theory

In contrast to NA, GT has developed technical and rigorous procedures concerning the methodology and method, although initially Glaser and Strauss (1967) suggested that readers use GT strategies flexibly (Charmaz 2006).

In developing constructivist GT, Charmaz (2006) proposed a return to a flexible approach with an emphasis on 'action' as central to the process of analysis. Thus she provided guidelines rather than techniques through which GT can be applied (Charmaz 2006:9). Charmaz (2014) provides a description of the process of analysis GT which is summarised later in this chapter.

Application of the concepts and processes involved in GT is described as an iterative and cyclical process, in which researchers develop insights and enrich categories as they engage in the process of analysis and further theoretical sampling (Charmaz 2014). Ultimately Charmaz (2014) suggests that theory development occurs. She defines theory in this context as "*aiming to understand meanings and actions and how people construct them. Thus these theories bring in the subjectivity of the actor and may recognise the subjectivity of the researcher"* (Charmaz 2014: 231).

Finally, Charmaz (2014) describes nine key actions that determine whether a piece of research has utilised GT methodology (Table 4.2):

Table 4.2: Distinctive strategies used by grounded theorists (Charmaz 2014: 15)
1. Conduct data collection and analysis simultaneously in an iterative process
2. Analyse actions and processes rather themes and structure
3. Use comparative methods
4. Draw on data (e.g. narratives and descriptions) in service of developing new conceptual categories

5. Develop inductive abstract analytic categories through systematic data analysis
6. Emphasise theory construction rather than description or application of current theories
7. Engage in theoretical sampling
8. Search for variation in the studied categories or process
9. Pursue developing a category rather than covering a specific empirical topic

In the current study, I chose to adopt a constructivist approach to GT. I sought to use GT to identify the meanings families gave to the challenges associated with bvFTD and the actions they engaged in to address its impact upon their lives and their relationships, using the strategies described in table 4.2.

Research design

Figure 4.1 below outlines the process engaged in to explore the research aims and questions identified in Chapter 2.

Figure 4.1

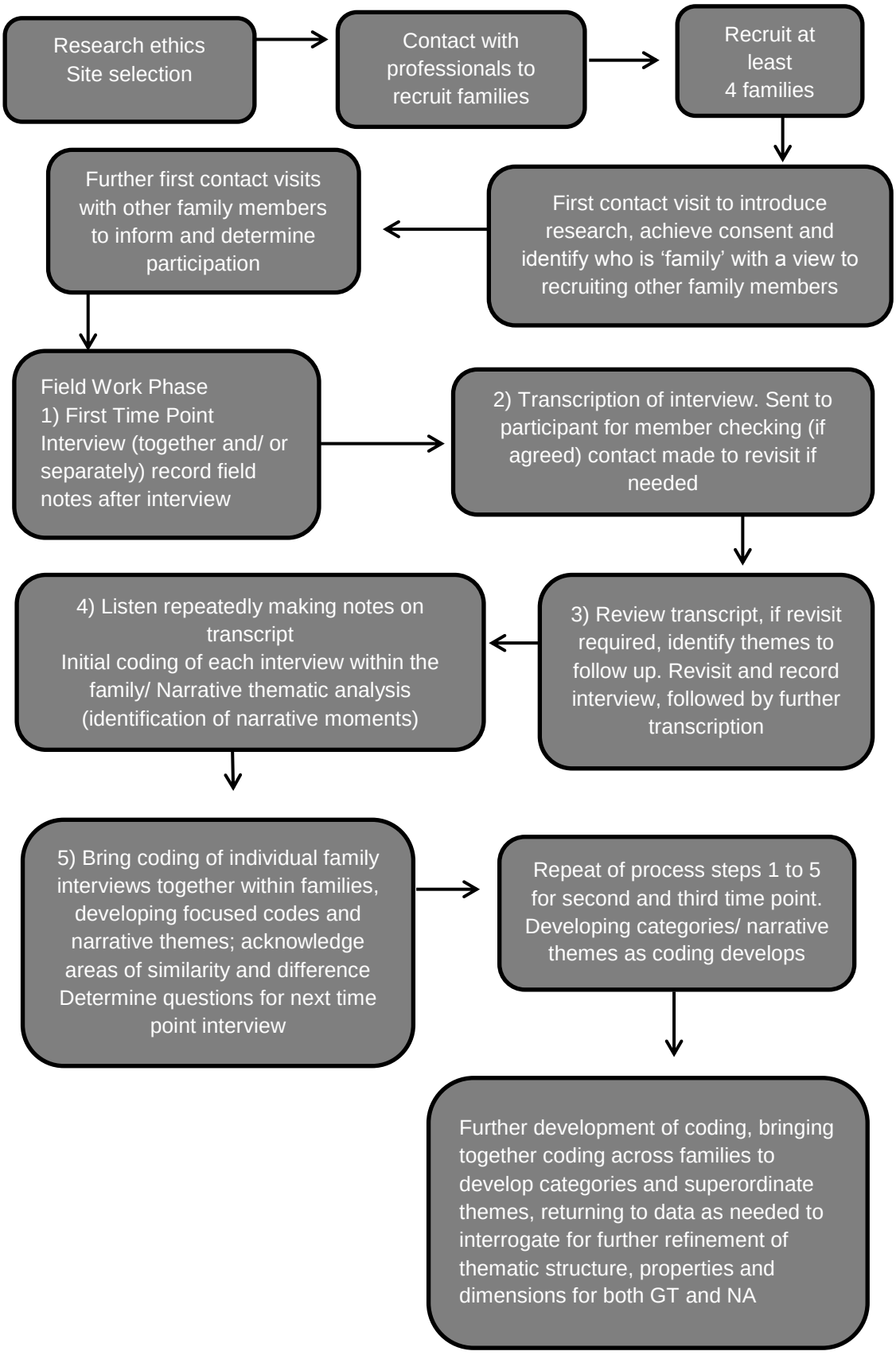

Research ethics
Site selection
Contact with professionals to recruit families
Recruit at least 4 families
First contact visit to introduce research, achieve consent and identify who is 'family' with a view to recruiting other family members
Further first contact visits with other family members to inform and determine participation
Field Work Phase
1) First Time Point Interview (together and/ or separately) record field notes after interview
2) Transcription of interview. Sent to participant for member checking (if agreed) contact made to revisit if needed
3) Review transcript, if revisit required, identify themes to follow up. Revisit and record interview, followed by further transcription
4) Listen repeatedly making notes on transcript
Initial coding of each interview within the family/ Narrative thematic analysis (identification of narrative moments)
5) Bring coding of individual family interviews together within families, developing focused codes and narrative themes; acknowledge areas of similarity and difference
Determine questions for next time point interview
Repeat of process steps 1 to 5 for second and third time point. Developing categories/ narrative themes as coding develops
Further development of coding, bringing together coding across families to develop categories and superordinate themes, returning to data as needed to interrogate for further refinement of thematic structure, properties and dimensions for both GT and NA

Figure 4.1 outlines in broad detail the research design. The following sections provide detail concerning each of the steps.

4.3 Ethical Approval

The NRES ethical approval process for recruitment within NHS sites was completed. This included applying for NHS ethical approval for participants who may lack capacity to consent. NHS Ethical approval was given on the 2nd December 2011 (see appendix 6 PDF on CD). Amendment to ethical approval was required and approved on the 25th of October 2013 following transfer to the University of Bradford (see appendix 7 PDF on CD).

4.4 Recruitment

The research population

The family were considered to be the unit of study. Within this context, the research population involved people who had received a diagnosis of bvFTD from an NHS dementia assessment and diagnosis service and their family members.

Site selection

A rural county within the West Midlands was chosen as the site for recruitment. This area was selected because I was familiar with and known to the NHS services and professionals within the area and would be able to provide signposting for support should this be needed.

Sampling and inclusion criteria

I used a combination of purposive (selection of a population with specific characteristics) and snowballing sampling (using existing participants to recruit others known to them). I sought to recruit people who had received a diagnosis of bvFTD from a specialist mental health or neurology service. Additionally, I sought to involve their family members as defined by the person and their closest family. This included partners, children, parents, siblings and other close relationships (Kendall et al. 2010; Roach et al. 2014b). Where relevant to the person with bvFTD and their close family, the research would involve two or more generations in each family. Furthermore I

aimed to recruit families who reflected a range of experiences associated with bvFTD, including those;

- Who had just received their diagnosis or were just beginning their experience of living with the condition.
- Who were later in the experience of living with bvFTD and the person is still living at home or;
- Where the person living with bvFTD had moved into institutional care or was reaching end of life.

The exclusion criteria were:

- If the person diagnosed with bvFTD already had a pre-existing, unrelated neurological condition such as Parkinson's disease, as it would not have been clear what impact this additional condition would have had upon the family experience
- Children within participating families who were below the age of 6, as it would have been difficult to ensure true assent to participate and there are acknowledged challenges for children as young as this to participate in the demands of qualitative interviews (Allmark, 2002, Balen et al. 2006).
- Families where the first language spoken was not English and where interpreters would be required. The use of interpreters is known to be problematic in regard to effective data collection and poses great challenges to authenticity and rigour (Squires 2009).

This type of research frequently involves small sample sizes. However, due to the nature of the methodology involved, it generates a significant data set, particularly when interviewing every six to nine months as was the intention in this study (Holland et al. 2006, Yates, 2003). The sample size was therefore selected to reflect the quantity of data commonly collected in qualitative longitudinal research (QLL).

Recruitment

Recruitment occurred through NHS services, including dementia assessment and diagnosis services, community mental health services, specialist nursing

services and peer support. Meetings were held with professionals to explain the study and written information was provided. Recruitment, packs were supplied and contact could be made directly with the researcher or via a professional.

Initial contact with interested families

Seven families were ultimately recruited. Contact with all of the families came through a professional, who contacted me directly. I asked professionals for general information concerning the families (within the boundaries of confidentiality). This included;

- How the diagnosis of bvFTD had been established and who had made the diagnosis
- Whether they believed the person with bvFTD was able to give informed consent
- Whether there was specific information I needed to know to support the family and in particular the person with bvFTD appropriately during the consent process
- What terms were used by the family and the person with bvFTD concerning their diagnosis

I made contact with families to arrange a convenient date, time and location to see them. Initial contact was generally with the person with bvFTD and their closest family member. During this contact, the use of the term bvFTD or dementia only occurred if such terms were used directly by the person with dementia and their family in order to avoid inadvertent diagnostic disclosure and distress (Cowdell 2006).

If the person with bvFTD and their closest family member were interested in participating, recruitment of additional family members was discussed with them and they were provided with information sheets and consent forms to give to family members. On some occasions this resulted in contact details being passed to me, so I could approach them directly. I had varying degrees of success in facilitating contact with more than one generation through these processes. It seems likely that a range of factors influences the participation

of wider family members when using a snowballing strategy (Ribbens McCarthy et al. 2003). (This is further discussed in Appendix 8 pages 12-15. PDF CD).

Consent

Consent was sought from all family members, including the person with bvFTD. Consent was treated as an on-going process (Wilkinson 2002; Dewing 2007; Hellström et al. 2007b). That is, I sought to provide information and clarify the views of individuals within the family about their continued participation in the research each time a visit took place. In this context I used a reflexive approach, maintaining vigilance throughout with regard to the verbal and non-verbal indicators of consent. Furthermore, I maintained a research diary to record reflections. I discussed these as appropriate in research supervision to ensure that the rights of participating families were upheld. Consent was addressed in the following stages;

Consent with Family Members

I provided an information sheet (appendix 9 PDF CD) and discussed the research aims and process with family members. During this process, I assessed the capacity of each family member to give informed consent in accordance with accepted practice (Department of Health 2005). This involves determining if a person:

- Can understand the information provided
- Is able to retain the information for sufficient time in order that;
- They can consider the request being asked and make a judgement about their participation and;
- Can communicate their decision (by any means)

I offered family members time to consider their participation in the research, however most were happy to provide written consent at the end of the meeting (appendix 10 PDF CD). I nevertheless indicated that I would be checking at each contact if they were happy to continue. Furthermore, I informed them that they could stop at any time and that their non-participation would not result in any changes to the care that they received at

that time or in the future.

Consent with Person with bvFTD

As a consequence of my professional and research experience, I was aware that consent with people with bvFTD could be challenging. Previous studies have found changes in a person's capacity to consent and awareness of the research during the course of the research and in their willingness to participate (Pratt and Wilkinson 2001; van Baalen et al. 2011; Nygård 2006; Hellström et al. 2007b). I sought to establish ongoing consent through providing explanations and observation of verbal and non-verbal cues at each point of contact with the person with bvFTD (Hubbard et al. 2002). This was particularly important when I changed employment, as this resulted in some research participants being in contact with me through my service development work. I was therefore very careful to clarify the purpose of my visit and the nature of the work we would be doing together.

Achieving informed consent was a two stage process with people with bvFTD. Firstly, I sought the views of referring professionals concerning capacity to consent in order to determine if consultee consent was required prior to contact with a family. I also asked for any information from professionals concerning indicators of well-being and ill-being in the person with bvFTD that would enable me to judge the impact of the discussion on them (Dewing 2007). In the opinion of the referring professional, all of the persons with bvFTD who ultimately participated were considered able to give informed consent.

Secondly, I arranged to meet with the person with bvFTD and provide a tailored information sheet (appendix 11 PDF CD). People with bvFTD were given a choice about who they wanted to be present during these meetings; all but one chose to have a trusted family member present. Capacity to consent was assessed in accordance with the criteria outlined above. All who participated were able to give written consent and capacity was assessed on an ongoing basis at each contact.

The participating families

Seven families were recruited over a period of 18 months. All names and identifying details of participating families have been changed to preserve confidentiality. Pseudonyms have been used. Details are provided in table 4.3 below.

Table 4.3 Characteristics of participating families

Family	Name	Age at T1	Relationship to person living with bvFTD	Length of time since symptoms first acknowledged by family	Length of time since diagnosis	Receipt of Services at time of research
Burton	Anthony*	64		3 years	2 years	One to one support
	Mollie	62	Wife			Admiral Nurse
	Jane	35	Daughter			None
Horton	Penny* #	64		12 years	4 years	Care home
	Phil	65	Husband			Admiral Nurse (T1)
Hugh	Elizabeth * #	81		7 years	5 years	Home care
	Pamela	55	Daughter			Admiral Nurse
	Jonathan	57	Son in law			
Lewin	Ray *	64		5 years	4 years	Home Care
	Sarah	35	Daughter			
	Alex	43	Son in law			
Morris	Bert*	66		3 years	2 years	None
	Melinda	64	Wife			None
Perrin	Alistair *	54		7 years	4 years	One to one support (T3)
	Kate	53	Wife			None
	Rachel	27	Daughter			None
	Rena	78	Mother in law			
	Dave	79	Father in law			
Stuart	Terry *	65		2 years	2 months	One to one support
	Sue	66	Wife			Admiral Nurse (T1)
	Carole	35	Daughter			None

(* person diagnosed with bvFTD, # person did not take part in research)

As can be seen from the table above, the seven families included five people living with bvFTD, five partners, five adult children, two sons-in-law (to the person with bvFTD) and two parents-in-law (to the person with bvFTD). Time from first noticing symptoms to diagnosis ranged from one to eight years.

Time since diagnosis ranged from two to five years at the first time point of the research. All participants with bvFTD and their closest relative were in receipt of services at the beginning of the research but not all continued to receive support over its duration. All participants were of white European ethnic origin.

Of the nineteen individual family members, all but three took part at all three time points. Two people (a couple) withdrew after the second time point due to family circumstances. One daughter also chose not to continue to participate after the second time point. Appendix 12 (PDF CD) contains details of my contact with family members over the duration of the fieldwork.

4.5 Data collection

Interviews

I chose to use a semi-structured interview as my main method for data collection. I interviewed family members separately and/ or together (depending upon their wishes) at 6 monthly intervals over a period of 14 to 24 months following recruitment, resulting in a total of 46 interviews at the end of data collection. Interview duration was 20 minutes to 1hour 40 minutes, with the majority lasting around one hour.

In keeping with both GT and NA, I chose a flexible, narrative biographical approach to interviewing (Charmaz 2006; Riessman 2008) in which I sought to facilitate opportunities for families to provide extended narratives concerning their experiences.

Both GT and NA acknowledge the value of sensitising concepts and disciplinary perspectives in informing the research process (Charmaz 2006). I developed a flexible interview guide which was informed by my professional experience, existing literature concerning family functioning and relationships in the context of dementia (c.f. Rolland 1994; Hellström et al. 2007a) and discussion with my supervisors and professional colleagues (Appendix 13 PDF CD). Interview topics included the nature of family relationships, understanding of bvFTD, the experience of living with bvFTD and the strategies that family members used to cope with these experiences. As a part of the process of development of the interview structure, I considered my

own responses as a way of addressing possible areas of bias I may have held (Birks and Mills 2011).

My approach to the interviews was to allow families to approach the topic in the manner best suited to them. Thus I often asked an opening question and prompted exploration of specific areas as appropriate (Charmaz 2006). This meant that families generally covered topics in the order that was most meaningful to them in a conversational style. Family members were interviewed together or separately depending upon their choice. This was reviewed at each time point. Second and subsequent interviews were informed by previous interviews. Thus interview themes were specifically developed for each individual or family group while maintaining a perspective on issues and themes that might have relevance across families or individuals (see appendices 14 and15 for an example of second and third time point interview guide PDF CD). All interviews were audio recorded with the permission of participants. Feedback was sought at the end of interviews and where necessary, information was provided to respond to any areas of concern or well-being needs of participants.

On occasions, follow-up interviews were needed. The possibility that this might occur had been discussed with families. Follow-up interviews reflected the needs of the person with bvFTD, the needs of the family or my own feeling that there were areas that had not been covered. Furthermore, I also explored sharing written copies of transcripts with them, in order that they had control over what was included in the transcript, as well as providing them with the opportunity to provide further details if they wished to. Not all of the families wanted to see their transcripts or felt that there was a need to have a further meeting.

While my role was clearly defined as a researcher in these interviews, my practitioner status was a strong influence on my conduct. Given the challenges experienced by people with bvFTD, my knowledge and experience enabled me to be sensitive to signs that they needed a break or wanted to stop as well as being vigilant for signs that they might be distressed. Additionally, given the sensitive nature of the discussions, it was important to be aware of this for all family members.

My practitioner experience and knowledge was particularly valuable during these times as I was able to attend to distress and explore support needs where this was necessary. Wherever possible, discussions about support needs were contained to the end of the interview. However there were occasions where it was appropriate to stop the interview and address participants' needs before checking whether they were ready or wished to continue. The challenges of managing the interface between my role as a researcher and my position as a Nurse is further considered in the section on reflexivity and reflection in this chapter and in Chapter 6.

Observational and Field Notes

To address the limitations identified by Riessman (2008) in narrative thematic analysis, in addition to interviews as the primary method of data collection, I kept a field diary which was used as an additional source of data in analysis. There were two purposes to this. Firstly I used it to record thoughts and observations at each contact with the family, in particular noting any relevant actions or interactions that might reveal their experience as it is lived. Secondly, it supported reflection on the impact of the research upon the families involved and was used within supervision (Murray et al. 2009, Holland et al. 2006).

Data Storage and Security

All data arising from interviews and contact with participating families was stored in a password protected file on a computer. Consent forms and identifying details were kept in a locked cabinet within the University department hosting the research. All identifying details including names and locations were changed at transcription and details of pseudonyms used were known only to my supervisors and I. Pseudonyms were used in field notes and in discussions within personal supervision. In accordance with the requirements of ethical approval, all audio recordings were deleted at the end of the writing up phase of the research.

Researcher Reflexivity and Reflection

I am a registered Nurse and therefore governed by the Nursing and Midwifery code (NMC 2015) in regard to my standards of practice and conduct. In professional practice reflexivity requires a person to reflect *on* and *in* action (Schön 1991). Thus I needed to consider how I would conduct myself while undertaking the research and consider methods to reflect on my practice.

I chose firstly to engage in personal as well as research supervision to address the emotional impact of the research on myself and to consider how my responses might impact upon the research process (Hollway and Jefferson 2013; Murray et al. 2009; Holland et al. 2006). This form of reflexivity is of particular importance in qualitative longitudinal research, where families may be vulnerable and become dependent on the researcher (Holland et al. 2006).

Furthermore, consistent with my professional practice, in which it is expected that I would reflect while engaging *in action*, I chose to adopt ethical mindfulness (Warin 2011; Bowtell et al. 2013), an approach which requires a researcher to be open to discomfort or difficult feelings within themselves that may indicate that an incident has raised an ethical challenge. It is suggested that researchers should view these as important moments in which openness and reflexivity is required in order to consider how best to respond in the moment (Warin 2011; Bowtell et al. 2013).

Given the sensitive nature of the research, there were specific ethical issues that I could prepare for. These included how I planned to conduct and end each interview. Thus in all periods of contact, I sought to be reflexive in considering the impact of the research and the needs of the family, allowing for breaks and ending the process as appropriate. Furthermore, at the end of the interview, I sought feedback and offered debriefing where necessary to discuss any issues that might have arisen. I also provided information about support services as this was required by research participants. In addition, I sought to facilitate appropriate endings to meetings, often by discussing

pleasurable events that had been raised by the family during the interview (Mason and Wilkinson 2002).

I also explored methods of addressing appropriate endings to the research relationship, given the particular challenges associated with longitudinal research. This included addressing support needs, gaining feedback on their experience of participating and providing them with feedback on the ways in which the research had already been used. Many of the participating families had expressly identified that their reason for participating was to assist and help others living with bvFTD. Therefore the provision of information about the ways in which the research was being used was particularly valued by them. The majority of families also requested a summary of the research when this was completed.

Additional ethical issues which occurred prior to and during the interviews specifically required me to reflect upon and adjust the approach I used. These included:

- What is considered to be data?
- Interviewing families separately or together
- The use of power in research interviews and specifically:
    - The needs of people living with bvFTD in interviews and their ability to control what they share
    - The sharing of transcripts with participating families
- Confidentiality within and across families.

The majority of these are addressed in Chapter 6 when considering the research context for each of the families. Therefore I shall address only two of them here.

What is considered to be data?

Interviewing people with bvFTD alongside their closest family member highlighted specific moments that caused me to consider whether interviewing could capture the complexity of the experience of bvFTD. A specific incident in which this occurred is outlined in appendix 8 (PDF p15-18). Although I had sought to record observations as a part of my fieldwork

diary, these incidents caused me to reflect on my interview style and how this complexity could be captured. Accordingly, I reviewed my practice and adopted techniques from the free association narrative interview method described by Hollway and Jefferson (2013). This enabled me to consider ways of addressing topics that might facilitate participants to consider life as it is lived. It also assisted me to be sensitised to moments which reflected this, particularly when interviewing family members together. I wasn't always successful in using this very open approach; indeed it wasn't always appropriate, particularly for people with bvFTD. However, the feedback I received from participating families suggested that they appreciated the conversational style that I adopted and the freedom they had to discuss the issues of importance to them.

Interviewing families separately or together

Various authors have discussed the advantages of interviewing couples together, including providing opportunities to see the relationship in action, thus reflecting life as it is lived (Holstein and Gubrium 1995; Bjørnholt and Farstad 2014). However, there are also potential disadvantages including the risk of conflict between couples in interview (Sakellariou et al. 2013). One such moment is described in appendix 16 (PDF p.18-21 CD). I utilised research and personal supervision to consider ways in which I should address possible conflict. This included reinforcing the need to provide opportunities for breaks or to stop the interview, as well as providing space for those participating to debrief and consider support needs at the end of the interview (Sakellariou et al. 2013). It also highlighted the value of supervision in being able to identify and address difficult feelings to limit their enactment within the research interview. Finally, it was important to acknowledge the need for flexibility. There is considerable value in carrying out serial interviews as this facilitates the opportunity to follow up issues arising in earlier interviews. However, a primary consideration should be the needs and capacity of the family to engage in this way. Not all families felt able to commit to this and I was mindful when this was the case.

4.6 Analysis of data

Transcription

All interviews were independently transcribed. Verbatim transcripts were produced. Where participants agreed, transcripts were sent to them and contact was made to check if they were acceptable, if there was more that needed to be included, or if particular issues needed removing. Only two family members asked for some content to be removed from two interviews. Following this, names and identifying details were changed to preserve confidentiality. After this process, tapes were repeatedly listened to and notes made on written transcripts, including reflecting on tone of voice, significant moments and pauses or gaps. Fieldwork notes were consulted and added where necessary to the written copy of the transcript. Electronic versions of transcripts were loaded onto NVivo 10 (QSR 2010).

Process of narrative thematic analysis

Riessman (2008) suggests that narrative thematic analysis should not fracture the data, but rather interpret the narrative as a whole. Furthermore, she indicates that researchers should seek to work with one interview at a time to identify narrative moments following which, coding occurs to illustrate general patterns across cases. In order to achieve this, she suggests that the processes of transcription and analysis cannot easily be distinguished as the researcher is required to develop an in-depth familiarity with the data through repeated immersion in it (Riessman 1993).

Gubrium and Holstein (2009) describe specific features of analysis when considering narrative accounts of close families. These include that the researcher should:

- Be aware of the metaphors about family life that might influence the telling of the story and the researcher's approach to analysis
- Take account of the way in which stories about family life are constructed and the purpose they might serve. How do these stories reflect the family's sense of who they were and are?

- Consider how particular members of the family are characterised, e.g. the person you can rely upon to support you or not
- Consider how these accounts within families differ or complement each other; are there different accounts and if so how are these expressed?
- Consider how stories are told in terms of we, us, I, you and them, as well as temporal references, for example, us then and us now

Gubrium and Holstein (2009) also suggest that the task of analysis is to explore areas of similarity and difference within and across family narratives. However, as Ribbens McCarthy et al. (2003) indicate, this is a privileged and powerful position for the researcher and requires that they reflexively consider their influence. This is particularly important when considering the themes that are identified, as it may be difficult to determine whether participants' accounts mean the same thing when grouping their narratives together (Esin 2011). Accordingly, Esin suggests that it is important to provide detailed descriptions of the thematic categories as well as the context so congruence can be judged. Finally, it is explicitly acknowledged in NA that relevant theory can be helpful in developing analysis; for example thematic categories can be informed by existing theory (Esin 2011). In the current study, the characteristics of families drew on systemic theory to inform the development of the continuum from *cohesive and connected to distant and disconnected* (Rolland 1994; Kissane and Bloch 2002).

NA was an iterative process in which interviews were subjected to initial analysis and the results used to inform subsequent interviews with family members throughout the study (Murray et al. 2009; Holland et al. 2006). The process of narrative analysis is outlined in Table 4.4:

Table 4.4: process of narrative thematic analysis	
1.	At each time point, interviews for each family member were transcribed individually
2.	Repeated listening to transcript, making notes on a written copy. Notes included identification of narrative moments in the text, intonation, pauses and researcher influence on production of narrative. Also considered others' influence on speaker where present in interview. Notes made concerning narrative context in which research occurred

3.	Identification of areas for further exploration with family/ individuals within family at next time point interviews
4.	Identification of core narrative moments in the transcript, relating to research questions 1 and 4, however these weren't separated from the whole textual account to preserve context. Listened to audiotape at the same time as considering meaning associated with narrative moment, as outlined by Gubrium and Holstein (2009)
5.	Thematic coding of narrative moments in NVivo, including the context within which the narrative theme was framed (Ross and Green 2011) (taking account of written notes). Where coding joint interviews, care was taken to identify who was narrating, whether it was a shared or an individual narrative
6.	Where more than one interview within a family was undertaken, themes identified were compared with each other to develop a thematic structure for the family narrative, which acknowledged similarities and differences in perspectives (Gubrium and Holstein 2009; Esin 2011) Themes were transferred to excel spreadsheets and colour coding was used to illustrate the perspectives of individual family members and shared narratives within the narrative thematic structure
7.	Following completion of interviews at all three time points, narrative moments for each individual and then each family were reviewed and brought together to form an overall narrative thematic structure for that family on an excel spreadsheet. Colour coding was used to represent individual family members and time points where codes occurred. (See appendix 17 for an example Excel CD)
8.	Comparison across all families to identify similarities and difference in the nature of the relationships. Development of superordinate and sub-themes: 1. Cohesive and connected ---- disconnected and distant 2. A changing we / I --- An entrenched we / I
9.	Revisiting transcripts and coding to verify thematic structure and refine analysis for each family and across families.
10.	Production of an account that details the research context, including the influence I had on the relationship with families.

Appendix 18 contains a description of the process of NA in this study, using the steps outlined above.

Process of grounded theory analysis

The processes which acted as guidelines for the conduct of the constructivist GT analysis are described in table 4.5:

Table 4.5: Main Steps in Constructivist Grounded Theory (Charmaz 2014: 18-20)	
Identification of research problem and initial research questions	Informed by sensitising concepts and general perspectives
Data collection	Following initial sampling
Initial Coding	Sticking close to the data, identifying codes line by line or incident by incident. Recognition that initial codes are provisional Coding is action focused (use of gerunds) Asking questions about the data to identify actions and processes An iterative process (coding one interview may lead to returning to another, to explore similarities and differences or gaps in the data) Use of participants' words to code data (in vivo codes)
Memo writing	Informal notes that allowed me to begin the process of interpretation and analysis of data early in the research Identifying ideas and insights and beginning to develop tentative categories. comparing codes and identifying links between codes This directed further data gathering, including returning to data collection and analysis of other data sets
Focused coding	Separating, sorting and synthesising data
Theoretical sampling	Obtaining more specific and selected data to further develop and refine emerging theory
Theoretical saturation	This occurs when no new conceptual relationships emerge that add further depth and dimensions to the categories that have been developed
Theory Building	Development of interpretive theory, to understand meanings and actions and how people construct them. Theory may involve multiple realities, acknowledges subjectivity "*offers an imaginative theoretical interpretation that makes sense of the studied phenomenon*" (231)

A more detailed account of the process of GT analysis in the current study is provided in Appendix 19 (PDF CD). The guidelines described above were adopted, although due to the heterogeneity within the small sample theoretical saturation was not reached and theory building was very limited (see chapter 10).

A pluralistic process

Frost (2011) suggests that *"a pluralistic approach can sometimes further enrich insight and provide a more holistic view of a phenomenon than can one method alone"* (191). In using narrative thematic analysis and grounded theory, I have sought to illuminate the reciprocal influence of family relationships and bvFTD. Using these two methodologies has facilitated a focus on how relationships are constructed over time as a consequence of

and in response to, the experience of bvFTD. Thus enacting the two methodologies has been a cyclical process, moving fluidly between each form of analysis when considering each transcript, each family and when bringing the results together. Ultimately this is reflected in the presentation of the results. For example, while the results of GT analysis is foregrounded in the presentation of the challenges experienced (Chapter 7) and the coping processes (Chapter 8), the influence of family relationships is evident. Similarly, in presenting the relational outcomes (Chapter 9), the coping processes illustrate how these outcomes are enacted within the family. However Frost (2011) indicates that pluralistic approaches can be accused of weakening the findings unless researchers are transparent in presenting how they achieved the results. With this in mind I now turn to consider the trustworthiness of the findings

4.7 Trustworthiness of the findings

The concept of quality in qualitative research is a contested area, influenced initially by debates more commonly associated with positivist research concerning constructs of validity and reliability (Elliott et al. 1999; Steinke 2004). These authors suggest that such debates have been flawed, as they fail to account for the underpinning philosophies of particular methodologies. Identifying criteria for qualitative research is further complicated by the range of methodologies and epistemological/ ontological foundations of such research (Elliott et al. 1999; Yardley 2000; Riessman 2008). However methods of evaluating quality are nevertheless essential in order to legitimise the value and meaningfulness of such research to those who might use it or benefit from it (Yardley 2000). Additionally, quality criteria can support reflexivity in researchers when undertaking qualitative studies (Elliott et al. 1999).

In Chapter 2, (table 2.2) a set of criteria for evaluating the quality of qualitative studies was presented (Elliott et al. 1999). The authors identify seven criteria which are especially important in qualitative research. Six of these are considered here. The final one, ‘resonating with readers’ can only be judged by the readers of this thesis.

Owning one's perspective

In this and earlier chapters, I have described my theoretical position, the personal and professional motivation for doing the research and my experience while undertaking the current study. I have considered the impact of my actions and strategies to address these in my relationships with the participating families. In Chapter 6, I provide an account of the research context for each of the families, which includes my feelings and experiences while working with them. While I have not used a first person narrative in the results sections, I have nevertheless sought to include my influence on participants by including my questions and prompts where appropriate. Furthermore, in the final chapter, I have considered my contribution to the findings. In addressing reflexivity throughout this thesis, I have aimed to provide an account of my influence, acknowledging that ultimately this account represents my interpretation of the experiences of these seven families.

Situating the sample

In this chapter, I have provided details of the participating families in order that the findings can be judged against similar situations or populations. This has included their age, gender, relationship type, time since first noticing symptoms and time since diagnosis.

Grounding in examples

I have provided examples of how I have undertaken analysis using grounded theory and narrative thematic analysis. Chapters 7 to 9 and the appendices to Chapter 6 provide a range of examples to illustrate the findings concerning the experiences of the seven participating families. A layered account is therefore provided (Frost 2011) that illustrates experiences within and between families and provides an account of the experience over time.

Providing credibility checks

A number of methods were used to provide credibility checks. Firstly, a family member of a person living with bvFTD agreed to be an advisor for my research. She has provided critical and supportive insights at all stages of

this research. Additionally she offered opportunities for reflexive discussions concerning the research process and emerging findings.

During the process of early analysis of transcripts, I provided my supervisors with my initial analysis of four interviews from one family. The emerging themes were discussed and consideration given to those that required further development. Supervision provided an important place throughout the analysis, for thematic development to be discussed and critiqued.

Following the tentative development of the narrative thematic and grounded theory coding frameworks, I produced an account of the grounded theory analysis and narrative thematic analysis for one family. I chose this family because their experience was significantly different from the others, thus providing a 'negative case' through which the coding framework could be considered and challenged. These two accounts, the transcripts for this family and the categories I had developed were reviewed by a clinical psychologist with practice expertise and research experience in the field of dementia care. A summary of his coding is contained in appendix 20 (PDF on CD). We discussed the coding framework he had identified. His analysis was largely congruent with my own, with one area, concerning a theme of resentment that I had not considered. This theme seemed important in relation to this family and was incorporated in my analysis.

The written accounts, transcripts and categories were also shared with the family caregiver described above. I also provided her with the research questions to guide her thinking following which, we met and discussed her thoughts about the transcripts and my coding. She considered the coding to be congruent with the issues identified within the transcripts.

Coherence

I have provided an overarching framework which integrates the results of the narrative thematic analysis with the results of grounded theory analysis. The resulting framework aims to provide a coherent, dimensional and nuanced representation of the experience within and between these seven families over time.

Accomplishing general vs specific research tasks

Elliott et al (1999) indicate that qualitative research seeks either to achieve a general or a specific understanding of a phenomenon. Where a general understanding is required, a broad range of experiences within that phenomenon should have been selected. Where a specific understanding is required, then the researcher should be able to demonstrate a systematic and comprehensive approach in which limitations are also discussed. In this research study, I set out to explore a specific phenomenon; considering the reciprocal influence of bvFTD and relationships for seven families over time. These seven families provided rich and detailed narratives concerning their experiences of living with bvFTD which I have analysed and interpreted to provide answers to the research questions. Strengths, unique findings and limitations of the research are discussed in Chapter 10, from which the extent to which the research has achieved the research aims can be judged.

4.8 Conclusion

In this chapter I have provided an account of the methods used to deliver a pluralistic, qualitative longitudinal research study which sought to explore the research aims and questions identified at the end of Chapter 2. I have described the way in which participating families were recruited, the methods used to obtain data and the process of analysis. I have also provided a reflexive account of my influence on the research and the way in which this was managed. Finally, I have considered the extent to which quality criteria for qualitative research have been addressed within this study. The next chapter provides an overview of the findings of this research.

Chapter 5 Introduction to the results

The next four chapters describe the findings of the research I undertook with the seven families. Four superordinate themes emerged. Additionally, a range of influencing elements were identified which impacted upon the experience of the challenges for family members. These themes had a reciprocal influence on each other as demonstrated in fig 5.1 below:

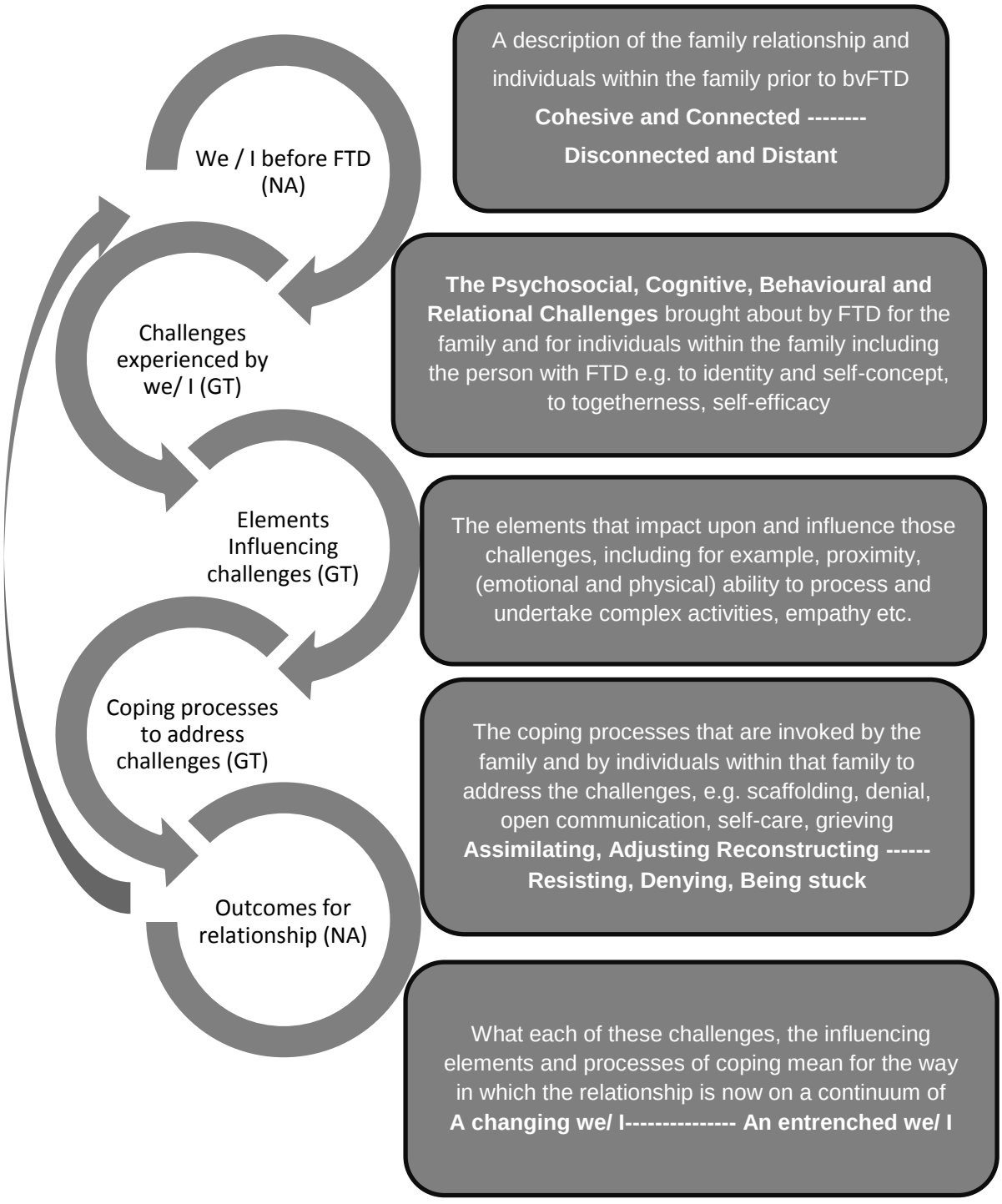


Table 5.1 provides an overview of the superordinate themes and the associated subthemes. It should be noted that theme 1 does not have subthemes whilst the sub-themes for themes 2 and 3 dovetail with each other, so are shown in parallel across the page. The sub-themes of theme 4 are shown at the bottom of the table.

Table 5.1 Superordinate Themes and Subthemes Overview

Superordinate theme 1:	**We/ I before bvFTD**	**Cohesive and connected** -------- **Disconnected and distant**		
Superordinate theme 2: Challenges experienced by we/ I	**Influencing Elements**	**Superordinate theme 3:** **Assimilating, adjusting, reconstructing** -------- **Resisting, denying, being stuck**		
Awareness and understanding of the changes	*Emotional and physical proximity, It's really subtle and difficult for others to see, Readiness to see and hear the changes, Prior relationship, Availability of knowledgeable and supportive professionals, Understanding of bvFTD.*	**Accepting and Assimilating** *It's dementia, we have to find a way through this*	--------	**Resisting and Blaming** *Resisting knowing, They are the problem, You're the problem, you don't work with us or help us, Distancing.*
Managing everyday life	*Availability of knowledgeable and supportive professionals, Accepting – resisting—rejecting, Awareness – Unawareness, It's really subtle and difficult for others to see, Past experiences of similar difficulties, Peer support, Prior relationship.*	**Enabling and Facilitating**	**Distancing, Managing and Controlling**	**Avoiding and Reacting**
		Underpinned by Collaboration, Adaptation, Communication, Addressing Conflict and Cohesion		

<table>
<tr><td rowspan="2">We're not the same anymore/ I'm not the same anymore</td><td rowspan="2">Awareness – Unawareness,
It's really subtle and difficult for others to see,
Living together by choice,
Prior relationship.</td><td>Accepting and Adapting
Accepting the changes and finding new ways of being together</td><td>Fighting
Resisting the changes, we're going to fight this together</td><td>Distancing and being stuck
Achieving Distance,
Being stuck.</td></tr>
<tr><td colspan="3">Accepting the need for a changing I
Grieving for a changing you and a changing we
Acknowledging the need for a changing I
Accepting the need for a changing I</td></tr>
<tr><td>Being me in the context of bvFTD</td><td>In step or out of step in our awareness of changes,
Family coping processes,
I trust my family's' ways of supporting me,
Sense of self,
The impact of bvFTD on social and cognitive functioning,
An important person in our lives --- he was just there really,
Understanding their emotional world.</td><td colspan="3">Maintaining Self:
I'm still me, still active and engaged with life
I'm still me there's nothing wrong
I'm still me, resisting negative perceptions
Maintaining Wellbeing:
Supporting safety and security (a collaborative process)
Holding them (family members)
To
Resisting and restricting (person with bvFTD)
Controlling, positioning and distancing (family members)</td></tr>
<tr><td>Superordinate theme 4:</td><td>Relational Outcomes</td><td colspan="3">An entrenched we / I -------- A changing we / I</td></tr>
<tr><td colspan="2">Relational outcomes for close family members including the person with bvFTD (along the continuum)</td><td colspan="3">A changing we, stronger in a different way
Losing we, but still connected
Losing you so losing we, together but separate
There is no we, just getting through it</td></tr>
<tr><td colspan="2">Relational outcomes for partners, adult daughters and their partners: the need for a changing I</td><td colspan="3">Becoming a new I ----- An entrenched I</td></tr>
<tr><td colspan="2">Relational outcomes for wider family members (along the continuum)</td><td colspan="3">Closer together
Conflicted
Losing 'we'</td></tr>
</table>

The first superordinate theme, *Cohesive and Connected ---- Disconnected and Distant* represented the bedrock of pre-existing family relationships upon which family members, both together and individually, sought to address the experience of bvFTD. Consequently, this is the first theme and is discussed in Chapter 6, which gives a summary of the relationships between family members as described by them prior to the onset of behavioural variant frontotemporal dementia (bvFTD). A full account of these relationships along with quotes is available in appendix 21 (PDF document CD). In this chapter I also consider the influence I had on the research.

In Chapter 7, the four *challenges* brought by the experience of bvFTD for these seven families are discussed, along with the *influencing elements* that impacted upon them and influenced them.

In Chapter 8, the coping processes that are invoked by the family and by individuals within that family to address the challenges are discussed on a continuum of *Assimilating, Adjusting Reconstructing ------ Resisting, Denying, Being stuck.* Coping processes associated with each of the challenges are addressed in turn. It is necessary to recognise that the challenges and coping processes reciprocally influence each other, thus strategies used by one family member may impact on others, sometimes posing new challenges and sometimes influencing their ways of coping. This complex dialectic is reflected in the close inter-connections between these two chapters.

Finally, in Chapter 9, I discuss the last of the superordinate themes; *A changing we/ I ----- An entrenched we/ I*. This chapter considers the relational outcomes associated with challenges and coping processes for the family as a whole and for individuals within the family. While the term outcome is used, this is not to imply that an end point has been reached, rather it represents the point at which the research ended. It is clear from the longitudinal nature of the research that relational outcomes in turn influence the way in which the challenges are experienced and coping processes are developed in a cyclical manner. A copy of table 5.1 is included on two A3 sheets at the end of chapter 9 which can be opened out and referred to as the results chapters are read.

Chapter Six: We / I before Behavioural Variant Frontotemporal Dementia (bvFTD): Cohesive and Connected – Disconnected and Distant

6.1 Introduction

In this chapter I present findings concerning the relationships of the 7 participating families prior to the onset of behavioural variant frontotemporal dementia (bvFTD). At the beginning of the first time point interview, where possible and appropriate, I asked the person with bvFTD and their primary family supporter to identify those who they considered to be part of their family. We progressed to exploring their perspectives on their family relationships prior to the onset of bvFTD. Similarly, other family members who had agreed to participate were also encouraged to discuss their family relationships and their relationship with the person with bvFTD prior to the onset of bvFTD. Beginning the interviews in this way proved to be an important cue for the focus of the research and appeared to support family members including the person with bvFTD to understand the relational focus of the interviews. For the majority of family members, this approach appeared to be experienced as non-threatening and was possibly a way of easing into the interview process.

A list of those family members mentioned in the family narrative is provided together with a genogram. Those family members participating in the research are highlighted in bold. A summary 'portrait' of each family is then provided; Appendix 21 (PDF CD) contains the full portrait of each family supported by quotes from their interviews. Family members' perspectives are presented individually within each family, following which family relationships are summarised, bringing individual perspectives together. In keeping with narrative analysis (Reissman 2009; 1993), I go on to discuss the interview context and my own experiences of interviewing the family members in order to provide a basis upon which my analysis can be judged for coherence, authenticity and trustworthiness.

6.2 Burton Family

The Burton family are a 3 generation family comprising of;

Anthony (who has bvFTD, aged 64)

Mollie (wife of Anthony, 62)

Annie (daughter of Anthony from a previous marriage)

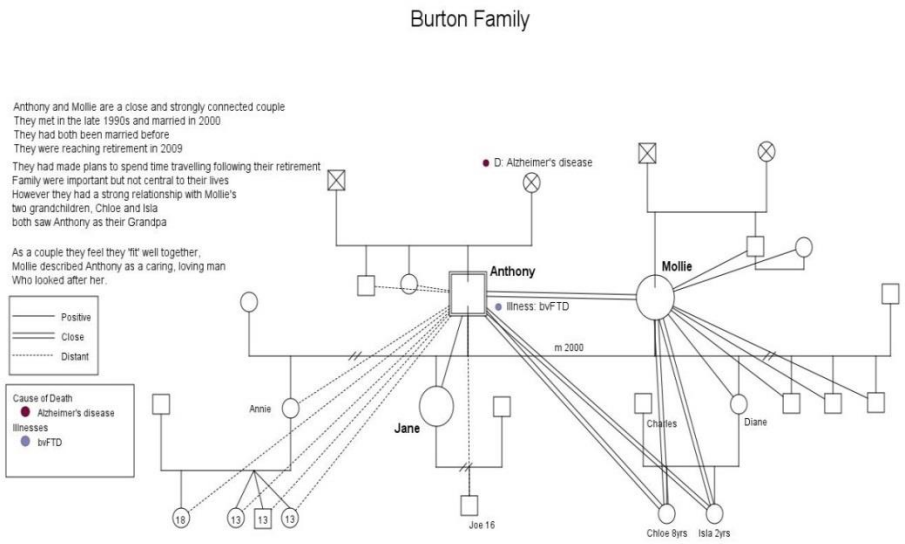
Jane (35, daughter of Anthony from a previous marriage)

Diane (daughter of Mollie from a previous marriage)

Joe (aged 16, son of Jane)

Isla (daughter of Diane, aged 2)

Chloe (daughter of Diane, aged 8)



The Family Relational History: A reconstituted family involving closeness and disconnectedness

Anthony and Mollie Burton

Anthony and Mollie first met in the late 1990's. They were both divorced with grown-up children and described having reached a point in their lives where they sought a new relationship. Anthony and Mollie married in 2000 and appeared to be close and strongly connected to each other. They described their lives as revolving around each other and the boat that they shared, with every opportunity taken to share the pleasures of life together.

Mollie appeared to experience her relationship with Anthony as different from her previous relationship and described how he had looked after her and cared for her. Prior to the onset of bvFTD, they were transitioning to a new phase of life, in which they were working towards retirement and appeared to have plans to spend increasing amounts of time together pursuing their shared leisure interests. This seemed to be a very significant decision for both of them, reflecting a hoped for future together as a couple.

While they described family as being important, relationships with wider family members do not appear to have been central to their lives together as a couple. For example they described spending Christmases together on their boat rather than with their family. Nevertheless, both appeared to enjoy their relationship with their grandchildren Isla and Chloe (Diane's daughters) and considered this to be a meaningful and positive relationship. Mollie also indicated that she had regular contact with her children and also with her brother and his wife. However Anthony appeared to be less connected to his family. He described distant and disconnected relationships with his siblings, his eldest daughter and her children and Jane's son. His younger daughter, Jane is the only person from Anthony's family of origin that they appeared to have regular contact with.

Jane Burton

Jane was the only other member of Anthony and Mollie's family who consented to take part in the research. However, while she participated in two of the time points and is happy for her data generally to be included, she requested that specific quotes were not used to safeguard her privacy. While it is possible to include some examples from her participation in subsequent results chapters, including material about her in this chapter may compromise her confidentiality were it to be read by people who are close to her. Therefore her description of her relationships with her family are not included here.

Interview Context

Anthony, Mollie and Anthony's daughter Jane consented to participate in the research. Anthony seemed to understand the purpose of the research and was agreeable to his participation; however I revisited consent with him at each time point. Interviews were carried out with Mollie and Anthony together, although this was reviewed between us at the second time point of the research. Anthony and Mollie participated through all three time points, in a total of 6 interviews over 2 years which took place at their home. I was made to feel very welcome by them and it was evident from the outset that they were keen to participate.

A strong feature of the interviews was the level of commitment that the couple appeared to have towards each other, the happiness they experienced in meeting each other and literally as they put it, '*sharing the pleasures of life together'*. Our discussions were largely dominated by their experience of their relationship and the way in which they had adapted to the changes associated with bvFTD. I found their interviews to be very powerful and I experienced a strong emotional connection to them. Through reflection and discussion with my personal supervisor I was able to locate the powerful emotional connection to two major issues. Firstly I am also part of a 'blended family'. I was aware that I also shared some common ground including the hopes I held for the future with my husband.

Secondly, I reflected upon the way in which this couple were managing the challenges brought about by bvFTD. Through supervision, I realised that because of my previous experience of working with people with advanced experience of bvFTD and their families, I held a strongly negative perception of what bvFTD might be like. I realised that this was influencing my reflection on the interviews with Anthony and Mollie, in that I tended to focus largely on the losses being experienced and was initially surprised by their apparent adaptation. Recognition of this allowed me to consider their experience and

those of other families in a more balanced way and furthermore, be conscious of how these issues might influence my relationship with them and the analysis of their interviews.

As Anthony and Mollie were the first family to take part in the research, I was very conscious of 'trying out' my interview approach with them. Reflections on the approach I used with them after the interview and when I returned to see them to review the first time point transcript resulted in an opportunity to consider how I interviewed people with bvFTD. Anthony and Mollie reflected that sometimes I needed to give him more time to process and answer my questions. This was an important opportunity for me to learn from them. Furthermore, my initial approach to describing family relationships was to draw a genogram with them. Having reflected upon the experience with Anthony and Mollie, I changed to using a simple diagram and gave it to the families to draw, thus giving them control.

Jane Burton participated in interviews at two time points over 7 months, at a separate venue, away from her home or workplace at her request. Jane's engagement with the research felt tenuous from the outset. It took some time for her to consider whether she wanted to take part and I experienced some concern about whether she felt under pressure to participate. I stressed the importance of her right to choose, the confidentiality of her responses and her right to stop at any time, following which she consented to participate.

During the first interview it appeared that Jane experienced a high level of anxiety and sadness and although I gave her opportunity to withdraw or stop, she elected to continue. In the second interview, I was again concerned that Jane was not comfortable with the process, her answers were often short and she appeared to find it difficult to answer. I felt that the interview was at risk of becoming interrogative and unduly pressuring. Consequently I made the decision to end it. Following this, I discussed the concerns I had within personal and research supervision and decided to make email contact with Jane to reinforce her rights in regard to participation. I indicated that I was concerned that she was uncomfortable and consequently I would leave it

up to her to make contact with me should she wish to participate in a third time point interview. Jane did not take part in any further interviews.

6.3 Horton Family

The Horton family are a 3 generation family comprising of;

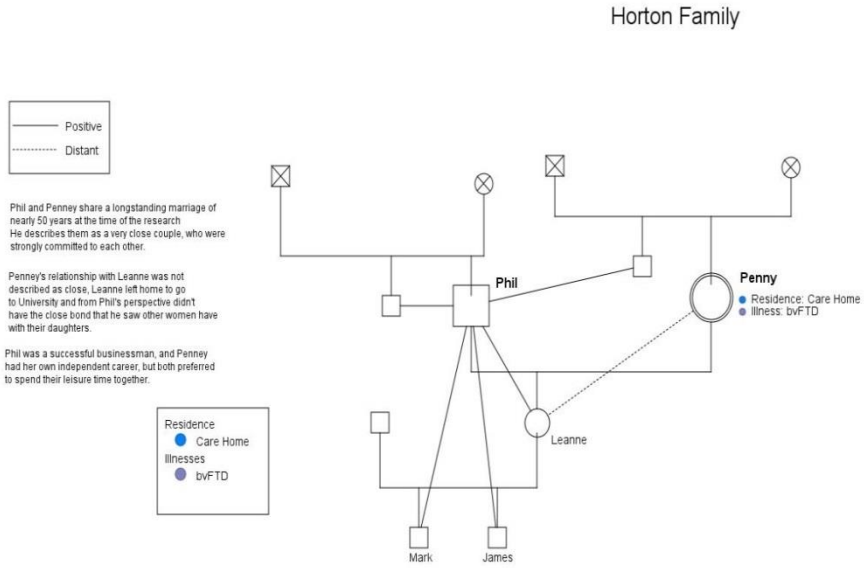
Penny (aged 64, who lives with bvFTD)

Phil (65, Husband of Penny)

Leanne (43, daughter of Penny and Phil)

Mark (aged 5, Grandson)

James (aged 6, Grandson)



The Family Relational History: It was just us but it was fine that way

Phil Horton was the only person in this family to participate in the research. Phil described a long-standing relationship of 50 years with Penny and appeared to feel strongly committed to her. He described a close and strong partnership in which many activities of married life were shared.

Phil and Penny also had independent careers that seemed to involve significant demands on their time as well as having active social lives. While it appeared that his work was an important part of his life and involved long hours and frequent international travel, it seemed that outside of work Phil had no desire to be apart from Penny.

Phil held a largely positive view of their lives together and indeed of Penny. When describing Penny, he focused on the many positive qualities he believed she had, including her sociability and her willingness to give of herself to him and to others. He felt that her career had been important to her and that she had established a life for herself while he was working, including undertaking voluntary work prior to and after she retired from her PA position. He also suggested that throughout their marriage, Penny was significantly involved in managing the day to day running of the house due to Phil's work commitments.

When discussing their wider family, Phil suggested that they had always had regular and frequent contact with their siblings who lived close by, although in recent years some of their siblings had passed away. Their daughter Leanne was born when they were 22 and 21 respectively. Although he didn't describe his daughter's childhood, he seemed to suggest that they had not had regular and frequent contact since she had left home. He felt that the relationship between Penny and Leanne was characterised by some distance. Leanne has subsequently had two children, James and Mark, however they were not born until after Penny had been diagnosed. Consequently although Phil described having a relationship with them, this appeared to be largely mediated through his contact with Leanne and did not appear to have been a shared grand-parenting experience with Penny.

Interview Context

My initial contact with this family was in meeting Phil after he had offered to participate in the research. At the time of meeting him to consider his participation and provide information, his wife Penny was in hospital and had been an inpatient for four months following a brief but difficult transition into a care home from their marital home. At that point in time Penny was very frail, had lost a significant amount of weight and Phil was concerned that she was nearing the end of her life. Phil and I explored whether it would be possible for Penny to participate, but due to her increasing frailty, lack of communication and her distress with unfamiliar people we agreed that it would not be appropriate. Phil however was happy to participate. I discussed

with Phil the possibility of Leanne being involved however ultimately, she did not take part.

Phil participated in all three time points over a period of 14 months, with these interviews being undertaken at his home. The consent visit and the first two interviews took place at the home that he had shared with Penny. Each time I visited his home during the first two time points, I experienced a sense of coldness and emptiness about the house. We sat in the lounge where the curtains were often drawn and I was aware of feeling that the house felt cold and unlived in. I found it significant that Phil suggested at the end of the consent visit, that it would have been better for us to meet in a local pub, which made me wonder if he was experiencing a sense of emptiness and loneliness. At the end of the first interview once I had switched the tape off, he described having brief relationships with other women but finding that this was not successful due to his commitment to Penny. My feelings about his home and the sense of isolation and loneliness he may have felt seemed to have been supported in later interviews. At the third time point interview Phil suggested that he had moved house because of the sense of emptiness he experienced once Penny had gone into the care home.

Interviewing Phil was different from the other interviews with family members who were primary caregivers as they were all female. Furthermore, the male partners with bvFTD lived at home and were earlier in their experience of bvFTD. It seemed to me that Phil was quite vulnerable and lonely. Consequently l was mindful from first contact that I needed to consider how I conducted our relationship and the contact we had. I also felt that I needed to consider what he may have wanted to achieve by being involved in the research.

Three issues became apparent in my contact with Phil. Firstly, I noticed in my initial contact for consent that Phil rarely appeared to use emotional language. Consequently I was mindful of the need to think about the way I phrased questions and how I interpreted his responses when undertaking analysis. For example, during the interviews, Phil did respond to emotion

focused questions when I used these, but his narrative frequently focused upon the things that they did and how this represented their togetherness. It was important that I did not make the assumption that this focus on the activities of their relationship implied distance, but may represent a different way of expressing how they were connected.

Secondly, I was also aware that throughout the early meetings with Phil, he talked at length about his work. It seemed that his sense of self was strongly tied up with his occupation and his identity as a businessman and that it was important to Phil that I understood this. This was enacted when I returned after the first interview, to review the transcript with him. Phil spent a lot of time during that meeting changing the content of the interview, to reflect grammatically correct English. For example, correcting when he had started a sentence with the word ‘and’. Indeed I felt that had I not reassured him, he would have changed significantly more than he did.

Thirdly, in between the first and second time point interviews, my work role changed and I became involved in work with people with dementia and their families in the area where Phil lived. Consultation exercises brought me into direct contact with Phil regarding his anger at the difficult experiences he had described with services. I discussed this within research supervision, as I was concerned about the boundaries between work and research with Phil, particularly given my concerns about his vulnerability. We agreed that if I felt that I needed to become significantly involved in the issues Phil had raised as a part of my work, then I would need to consider whether to cease data collection with him. Ultimately, this was not necessary as ongoing involvement with Phil in my work role wasn’t required.

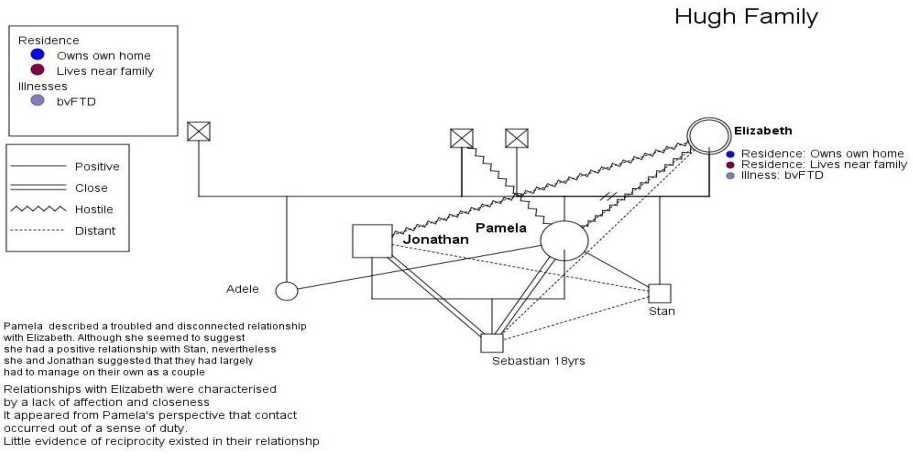
However, it is perhaps significant that as my research relationship with Phil progressed, he seemed to relax and appeared more trusting of me. He did not feel the need to correct the transcripts from the second and third time points and spoke more openly in these interviews about his experiences and feelings associated with his wife. It is possible that the contact through work had a beneficial effect on his view of me as someone he could trust. I was

however very aware of the responsibility I had to manage the boundaries with him in order that he was able to feel safe and contained while being clear about the nature of my work with him. This was particularly evident in the final interview, where Phil revealed a very personal and apparently painful issue that he had recently discovered about Penny. I elected to stop the interview and focus on his wellbeing, as I felt it was unethical to continue at that point. Although we did recommence the interview when he felt ready, I was concerned about the possible impact that his trust in me would have for my imminent withdrawal as the research was ending. Again I reflected upon this in supervision, particularly because he had said, albeit in a light-hearted tone that I was abandoning him, when I had reinforced that the research would be coming to an end. I felt it was important to address this in my final meetings with him, therefore I raised it directly with him and supported him to explore his options for support going forward.

6.4 Hugh Family

The Hugh family are a 3 generation family comprising of;

Elizabeth: Mother (who has bvFTD, 81)
Alfie: Elizabeth's third husband (deceased)
Pamela: Daughter (56)
Jonathan: Pamela's husband (57)
Stan: Pamela's brother (mid 50's)
Nick: Pamela's elder brother (deceased)
Adele: Pamela's stepsister from Elizabeth's third husband
Sebastian: Pamela and Jonathan's son (aged 18)



The Family Relational History: A distant and disconnected relationship

Pamela and her husband Jonathan participated in this research. Pamela described a relational history with her mother Elizabeth that had been dominated by distance and disconnectedness. While Pamela felt that her childhood was unremarkable, she nevertheless felt that her mother was not very maternal. Consequently she suggested that her grandmother and aunt were significantly involved in their upbringing as young children. However, Pamela described a significant shift in her relationship with her mother in her early adulthood, in the period during her parents' divorce. She experienced a sense of abandonment by both parents, but particularly by her mother at a time when she was vulnerable and needed their support. As a result of this experience of abandonment, she came to see her mother as self-serving. Furthermore, she held her mother responsible for the distance that was present in their relationship.

This distance appeared to have continued throughout her adult life. Pamela met and married Jonathan and subsequently they had a son. Pamela and Jonathan suggested that Elizabeth had little involvement in their son's life and was largely unsupportive of them as a family. They described contact based on a sense of duty rather than an emotional connection and suggested that her business and social life was more important to her. An apparent consequence of the difficulties within their relationship is that unmet expectations seemed to be a strong feature of their narrative. These expectations appeared to influence Pamela and Jonathans' view of Elizabeth, in that they positioned her as always putting her own needs first. Both Pamela and Jonathan provided examples of her behaviour in support of this view, which predated the diagnosis of bvFTD and occurred in her relationships with others as well as with themselves. Where closer contact with Elizabeth was necessary, Pamela equated this with feelings of being '*sucked dry'*.

Consequently, Pamela and Jonathan appeared to have experienced a lack of reciprocity in their relationship with Elizabeth. An outcome of this lack of reciprocity is that they have not felt close or experienced a wish to be close to her. Furthermore, Jonathan and Pamela also suggested that they have not had an extended network of close family relationships. While both reflected upon relationships of importance to them and in particular Pamela referred to close friendships, connections to the Church and to her stepsister, they nevertheless expressed the view that they have survived together, independently of their family.

Interview Context

Interviews were with Pamela and Jonathan, although he wasn't present for all of them. During my initial contact with them, I asked them to identify and approach others to be involved in the interviews. They did not believe that it would be possible to involve Elizabeth as Pamela indicated that she did not accept that she had dementia and would therefore not agree to being involved. I did not feel able to make a direct approach to Elizabeth as I would have been reliant on Pamela's introduction of the research to her and I was also unsure about the extent to which Elizabeth could have given informed consent to my visit. Their son Sebastian and Pamela's brother Stan did not participate in the research.

A total of four interviews were completed over a period of 14 months at three time points. Pamela was present for all four interviews; Jonathan was present for the first two interviews and half of the final interview. All four interviews were undertaken at their family home. A strong feature of all of the interviews was the level of intensity of emotion expressed by both Pamela and Jonathan concerning their experience of Elizabeth's difficulties since the onset of bvFTD.

My initial contact with them both to introduce the research revealed a couple who appeared to be experiencing a significant degree of stress. Pamela in particular seemed to find it difficult to focus on the consent process as she appeared to want to 'tell their story' almost immediately. In the first interview,

Jonathan's narrative appeared to reflect a sense of helplessness, whereas Pamela's narrative seemed to contain high expressed emotion.

Consequently, during the interviews with Pamela and Jonathan I experienced considerable pressure to 'fall out' of my role as researcher and be a helper. I felt pressure to do this because of my practitioner status and my concerns about the difficult relationship they appeared to have with many of the services that were involved with Elizabeth. Furthermore, my perceptions of their level of need for support to manage the situation they were experiencing also contributed to the pressure I felt to help them. I frequently felt that the interviews may have been an opportunity for them to 'offload'. Consequently I found it difficult to guide the process at times and also felt under pressure to offer solutions.

I attempted to confine any discussions about signposting or interventions that they were seeking for Elizabeth to the end of the interview. However, this was not always successful and I found myself slipping into responding to their experiences at times rather than maintaining an enquiring role.

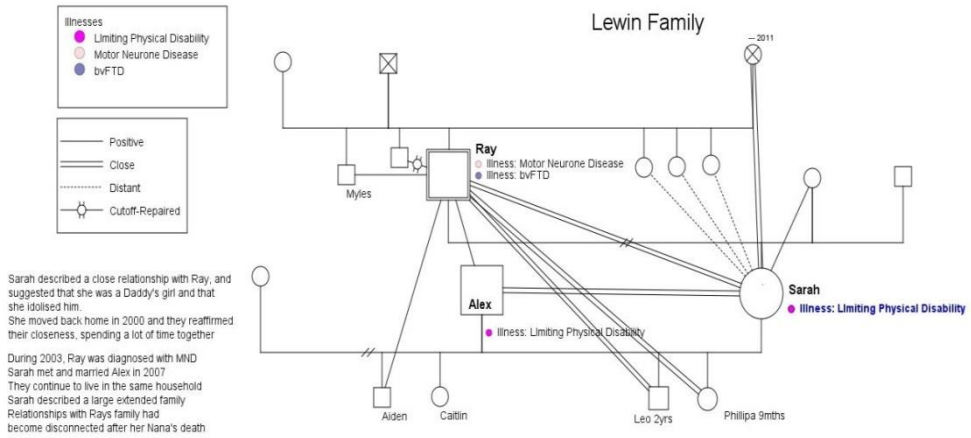
I experienced feelings of being overwhelmed at each interview and again when transcribing and listening to the tapes during analysis. I particularly found the level of emotional intensity challenging. I felt a degree of pressure to 'agree' with their view of the world and confirm their experience. Consequently, personal and research supervision and reflection were particularly important to manage the impact and to consider how my responses and analysis were influenced by this pressure. In particular, it was helpful to remind myself that their perspective represented only one aspect of the whole family narrative, other family members including Elizabeth and Stan and professionals are likely to hold different perspectives. Furthermore, my position in this research was to hear their story and experience and while listening to the tapes is an important aspect of this, there is a point at which I needed to bring a level of interpretation to the data, which means that immersion needed to be balanced with curiosity and analysis. Nevertheless, given the intensity of the interviews, I chose to offer these family interviews

for independent scrutiny by an experienced researcher and practitioner and by a family member who has lived with bvFTD so that I could check the veracity and trustworthiness of my analysis.

6.5 Lewin Family

The Lewin family are a 4 generational family comprising of;

Ray (aged 64, Father with bvFTD)
Sarah (35, Daughter of Ray)
Alex (43, Husband to Sarah)
Leo (aged 2, son of Sarah and Alex)
Phillipa (aged 9 months, daughter of Sarah and Alex)
Joyce and Eddie (Sister and brother in law to Ray)
Susan and Carrie (Sisters to Ray)
Barry and Jim (Close friends of Ray)
Aiden and Anna (Alex's son and daughter from a previous marriage)
Karen and Myles (Ray's step-mother and half brother)
Sian (Sarah's mother)



The Family Relational History: Me and my dad… and our family

Ray Lewin

Ray Lewin lives with bvFTD and Motor Neurone Disease (MND). Ray appeared happy to take part and seemed to understand the research context. Nevertheless, it seemed that Ray's lived experience largely focused

on his immediate life in the present. Consequently when asked questions about his family and their lives before bvFTD, Ray's responses were minimal and his narrative largely focused on his own history, rather than a relational history within his family. Thus the majority of the reflections on life before bvFTD were in terms of the work and activities that he was involved in, in which he suggested that he had experienced a full life. However it also appeared from his narrative that he believed that he and his ex-wife had led quite separate lives when they were together. He also appeared to feel that his involvement with Sarah while she was growing up was minimal and that his wife had brought her up. It is difficult to determine how much this perspective reflects the changes Ray has experienced as a consequence of bvFTD, such as changes in social cognition or whether it purely reflects different perspectives.

Sarah Lewin

In contrast, Sarah suggested that that she had experienced a close and connected relationship with Ray through much of her childhood. She felt that he was the stronger influence on her life as a young child and that she had a greater connection with him than with her mother. Indeed she described herself as a 'daddy's girl'. However, she explained that her parents divorced when she was 14 and suggested that their divorce marked a shift in her relationship with her Dad to one that was more conflicted.

However, in 2000, Sarah moved back home to live with Ray after separating from her partner. She suggested that this achieved a renewed closeness in their relationship, during which time she felt that he became her best friend, someone she relied upon and enjoyed life with. Indeed Sarah's narrative appeared to indicate a strong bond and a high level of commitment to her father. It was during this time that Sarah and Ray noticed changes in his wellbeing, which ultimately resulted in a diagnosis of MND in 2003.

In 2006, Sarah met Alex. He moved into the family home in 2007 and they subsequently married. Following this their two children were born in 2011 and 2012. Sarah appeared to suggest that they had a close network of

relationships, both family and friends. However after her grandmother died in 2011, she indicated that relationships had become distant with some of her father's family. Therefore, while Sarah described close connections with some family members, others including two of Ray's sisters appeared more distant. While Sarah appeared to feel family relationships were important, she seemed to suggest that there were some who had not been supportive. Given her father's earlier diagnosis of MND, this lack of support seemed to be a source of frustration for her. Nevertheless, she described some family and friends as frequent and regular visitors who supported them as a family.

Interview Context

The research with the Lewin family involved Ray, Sarah and Alex. They all live together with Sarah and Alex's two children, Leo and Phillipa, in a rural community in a house which is jointly owned by Ray and Sarah. A total of 8 interviews were completed over a period of 17 months. Interviews occurred with Sarah and Alex together (3 interviews), with Sarah on her own (1 interview) and with Ray on his own (4 interviews). The interviews took place at the family home, Sarah and Alex chose to be interviewed separately from Ray and our discussions were largely conducted in the kitchen. I met with Ray separately in the lounge. Ray was diagnosed with MND in 2003 and at the time of the research, was chair-bound and highly dependent for his physical care needs.

While Ray was happy to take part in the research, he mostly did not appear to acknowledge that he had dementia. Nevertheless, I was able to discuss the information and consent sheets with Ray and I believe that he was able to give informed consent to his involvement in the research. Consent to participate was discussed with Ray at each contact.

There were some challenges involved in interviewing Ray. He experienced difficulties with pronunciation given the impact of MND and it was sometimes difficult to understand what Ray was saying, particularly towards the end of the research, where his speech was markedly slurred. However, I found that

the main challenge involved Ray's apparent difficulty in moving beyond his own perspective and responding to questions about how Sarah and Alex experienced his difficulties and the impact on their relationship. This meant that although I asked these questions, he was rarely able to focus on them beyond a few initial comments. It was important that I recognised the limitations that bvFTD appeared to create for Ray and manage the questions I asked accordingly. Thus I was mindful of the need to accept his responses and not dwell on things that he appeared unable to consider. On occasions I found this quite a difficult balance to achieve, as he did appear to have occasional insights, but would rapidly return to discussing his own situation and experience of the world.

It appeared from my first contact with Sarah and Alex, that they experienced considerable difficulties with managing Ray's needs and the needs of their young family. As well as having two young children, they had explained that they both have long term health conditions which have a significant impact on their daily lives. However, the challenges they face appeared to be compounded by their apparent lack of understanding of Ray's condition and the absence of support they had received to address this. Consequently a feature of these interviews was that both appeared to experience significant frustration with Ray and his behaviour.

I recognised that I experienced a desire to fall into a helping role with them at times, given the challenges they appeared to be facing. Additionally, during analysis, I was also aware of experiencing some frustration with them because of the way in which Ray appeared to be positioned, as if he was to blame for the problems they were experiencing. Clearly it was important to step back from this to reflect on what might be influencing these feelings and consider how this might impact upon my research with this family. I discussed these issues in supervision and agreed that providing them with information about bvFTD and sources of support should they wish to receive these may be a useful response. I also worked at containing helping responses to the end of the interviews where possible. I reflected upon the feelings I was experiencing during analysis and what this might mean for my

interpretation of their experience. It was clearly necessary to avoid a blaming response in my analysis and acknowledge that all parties in this family have equally valid and different perspectives which need to be highlighted and reflected in analysis for it to be meaningful and balanced.

A specific feature of early interviews with Sarah was that she seemed to hold back from exploring her emotional experience of the changes that were occurring. Initially I wondered if recording the interviews was the problem, as she would on occasions talk about her experience after the recorder had been switched off. This presented challenges as due to the location, I was not able to record things we had discussed immediately after the interview and delays in recording risked that I would forget significant details. On one occasion, she reflected on her father's suggestion that the carers were meaningful to him in response to a question I had asked about who was important to him. She seemed to feel upset that he had put the carers before his family. This was the first time she had openly expressed her sense of loss. This revelation highlighted the value of ensuring that I found a way to record this as soon as possible to avoid losing valuable data. I therefore changed my approach to recording reflective notes by audio recording my thoughts as soon as I possibly could after each interview. This allowed for a much more immediate reflection on the experience with further notes being made later if needed.

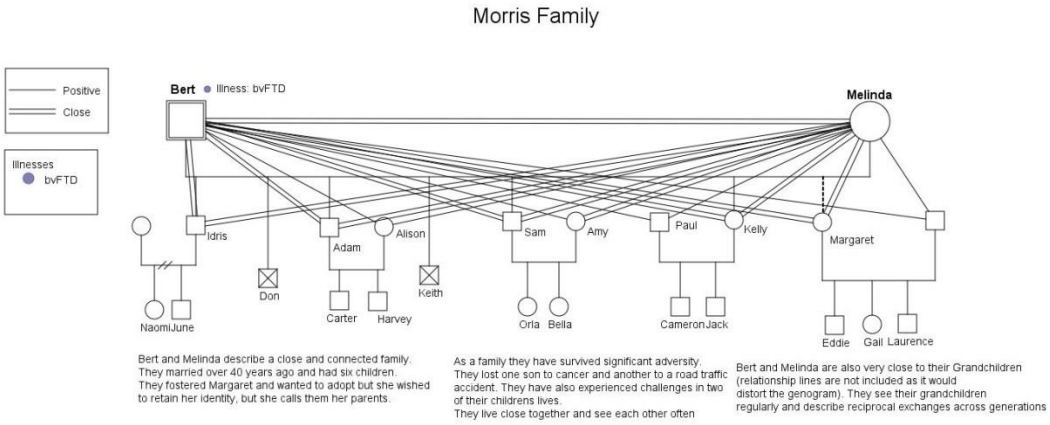
6.6 Morris Family

The Morris family are a 3 generation family comprising of;

Bert (aged 66, living with bvFTD)	Cameron (grandson)
Melinda (64, wife to Bert)	Orla (granddaughter)
Idris (eldest son, aged 41)	Naomi (granddaughter)
Adam (son)	Gail (granddaughter)
Sam (son)	Laurence (grandson)
Kelly (daughter)	June (granddaughter)
Margaret (daughter)	Carter (grandson)
Alison (daughter in law)	Harvey (grandson)
Paul (son-in-law)	Bella (granddaughter)

Amy (daughter-in-law) Jack (grandson)

Eddie (grandson)



The Family Relational History: We are family, close and interconnected lives

Melinda and Bert were the only members of their family to participate. They described having had a large family, with 7 children and 11 grandchildren. Their role as parents and grandparents seemed to be central to their lives. There appeared to be regular and frequent contact with their family which was described as important and meaningful to them both. Melinda and Bert seemed to feel they were a strongly connected and cohesive family. They had an in-depth knowledge and understanding of each of their children and grandchildren; valuing them as individuals in their own right and seemed to have a strong sense of their worth as individuals. This appeared to guide their role within the family, seeing themselves as there to support their children. However this did not preclude reciprocity and examples of support from their children to them were also evident.

They experienced considerable adversity in their lives, as two of their children had died in young adulthood and they had to contend with disability and ill health in 2 others. However, this adversity seems to have been viewed as a challenge to be managed together and they appeared to have supported each other through these difficult times. Melinda and Bert stressed the

importance of tolerance, understanding and acceptance of each other and their individual needs as fundamental to their way of coping. They also suggested that open communication with each other had been a fundamental part of the way that they have coped.

An important recurring theme in their story about their lives seemed to be that they have had to fight for the support that they have needed at different times. They described experiencing stigma when addressing the needs of two of their children and also when Bert was diagnosed with severe depression when he was 49.

Throughout their discussion of their lives together as a family, they did not describe their relationship as a couple in any depth. Outside of the interview, both reflected upon having been married for 45 years and described plans they had previously made to renew their wedding vows on their 50th wedding anniversary, although they had brought this forward due to Bert's diagnosis. Melinda suggested that Bert had been a loving and calm man before he experienced bvFTD. Furthermore, she felt that their children had loved him, looked up to him and respected him.

Beyond those family members described in the initial discussion, Bert and Melinda described close relationships with a couple who they had previously lived next door to and seemed to feel that they were more like family. They also described close relationships with one of their children's in-laws and went on holiday every year with them.

Interview Context

Initial contact for the research was with Melinda. During our early conversations, we explored participation of family members and initially, she indicated that she thought Bert might be reluctant to take part. I also explored the possibility of other family involvement, but Melinda felt that her children were not yet ready to participate, as it had not been long since his diagnosis. When I met with Melinda, Bert was present and did participate in discussions about the research. Ultimately Bert agreed to take part, particularly when I

explained that he could stop at any point. We subsequently explored different ways of encouraging family participation, including the possibility of recording a form of diary, but ultimately this was unsuccessful.

Following the consent visit, it was sometime before the first interview could take place due to difficulties relating to their housing, thus there was a gap of 6 months before the first interview. It was therefore necessary to revisit consent at the beginning of the first interview, to ensure that Bert was given the opportunity to revisit the reasons for my contact and make an informed choice about his participation. He agreed to participate. Subsequently, I was only able to interview Bert and Melinda at two time points, as a family crisis resulted in their withdrawal just before the third time point meeting. Therefore, Bert and Melinda took part in 3 interviews over a 12 month period. Interviews were together, at their home. My first contact with them was at a sheltered housing scheme in a small town in the West Midlands. However just after this they moved to a new bungalow with two bedrooms that was outside of the catchment area for the services they had previously been in receipt of. The interviews were conducted at their new home. Their home appeared to reflect the value they held for family life, with many photographs of their children and grandchildren in evidence, which they proudly discussed with me.

I was aware from my first contact with Bert and Melinda, that Melinda appeared strongly protective of Bert and her family. During the interviews I felt that this protectiveness influenced our discussions. It seemed that there were times when Melinda actively managed the nature of the discussions we had in terms of what was permissible or acceptable to discuss. For example, it seemed that it was difficult for Melinda to talk freely about the impact of bvFTD on their relationship as a couple. Although she did make a few comments in this regard, often they were outside of the interviews, in the kitchen or on the telephone rather than in front of Bert. Her comments appeared to indicate that the change in Bert had created a lot of conflict and tension between them, indeed she seemed to suggest that prior to the diagnosis the changes had put their marriage in jeopardy:

> *Gave clear indications that the initial experience was very challenging, "nearly broke us, nearly split up after 40 years of marriage" (field notes Bert and Melinda Morris, consent visit)*

Furthermore, it seemed that Melinda actively tried to manage Bert's feelings during the interview, steering away from topics which might be triggers for Bert's anxiety and frustration. For example in the first interview she repeatedly appeared to try and pacify him when he talked about his frustrations with the change in service provision in the new area.

However after the revisit at the second time point, it seemed to me that Bert was struggling with the interviews. Although he appeared to understand and want to participate, as we explored their experience, he became frustrated and upset about specific difficulties that he perceived were unjust, primarily relating to the provision of a wet room in their home. I also noticed that Melinda's nonverbal reactions seemed to suggest that she was feeling upset and frustrated. In order to support him, I listened to his concerns. Once the interview was over, at his request, I followed him through to the bathroom so he could show me what he was upset about. I then attempted to explore options for addressing his concerns about the wet room with them and promised to seek out relevant information. After reflecting upon this experience, I contacted Melinda to offer some possible contact points and also to discuss whether she felt able to continue with the research and to gain her views on the impact on Bert of participating.

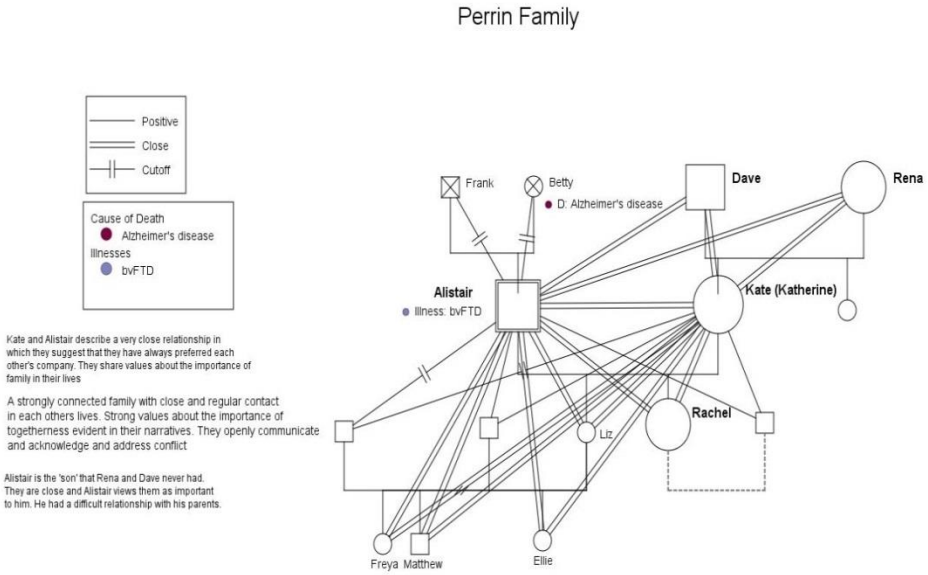
She stressed her desire to continue, but agreed that it was distressing for Bert. She also appeared to recognise that she was unable to talk freely in interviews with Bert about the impact on their lives and their relationship because of the effect she thought this might have on him. We recognised that we needed to identify a different way of approaching the interviews and agreed that it would be better to see her alone initially and then to see Bert if he was willing and able to participate again. I was also concerned to ensure that Bert was giving informed consent and had therefore intended to address consultee consent with Melinda before seeing Bert on the third time point.

However due to family difficulties, they withdrew from the research before the third time point interview.

6.7 Perrin Family

The Perrin family are a 4 generation family comprising of;

Alistair (aged 54, who has bvFTD)	Freya (Granddaughter)
Kate (aged 53, wife of Alistair)	Michael (Grandson)
Rena and Dave (74 and 79 Kate's parents)	Ella-Grace (Granddaughter)
Rachel (27, Daughter)	Sally (Kate's sister)
Liz, (Daughter)	Betty and Frank (Alistair's late parents)



The Family Relational History: We are family, close and interconnected lives

Alistair and Kate Perrin

Alistair and Kate met in 1982 and suggested that they had always been very close and did everything together. They further suggested that throughout their lives together, they have been quite insular, preferring each other's company to going out with others. They seemed to know each other well and work to each other's strengths. For example they indicated that Kate has

often been the driver of change and that Alistair has implemented them, but at the same time he also had clear boundaries about what he was prepared to do.

Furthermore open communication appeared to have been a fundamental part of the way they related to each other and within their family. They appeared to have shared values in regard to the upbringing of their children and worked hard together to ensure that their children had the things that were important to them.

Kate and Alistair appeared to agree on the central importance of family in their lives even though they seemed to have different views on who they defined as family. Kate appeared to have a broader network of relationships than Alistair who seemed particularly insistent that for him family was restricted to Kate's parents, their children and their partners and their grandchildren. They described regular and frequent contact with their family, on at least a weekly basis. This contact also included taking holidays together. They further described more recently, having regular Sundays together for dinner as a family. Indeed they appeared to suggest that being parents and more recently grandparents was a central feature of their lives together.

Kate Perrin

Much of the narrative about their lives together emerged during joint interviews between Kate and Alistair and was largely confirmed by Kate in her individual interviews. However Kate's narrative included further details about Alistair and their relationship. Kate suggested that Alistair had always been a patient and thoughtful man and was very caring; characteristics which she seemed to value greatly. Kate also felt that Alistair had a strong affinity with children and that this was an important part of his life, a value she seemed to share. Kate also emphasised that his thoughtfulness and care was valued by others including her parents, friends and his work colleagues.

While Kate suggested that he was loving and caring towards his family, these feelings did not appear to extend to his family of origin. Alistair himself had

not included them in discussions about who was important to him in the joint interviews. Furthermore, Kate and Alistair alluded to difficult relationships with Alistair's family and explained that Alistair had wanted different things for his children than he had experienced while growing up. Therefore Alistair appeared to have chosen to invest strongly in his relationships with Kate's family, including her parents, rather than with his family of origin.

Kate suggested that she has always been quite a practical person who was good at problem solving. For example, she described overcoming the challenges she faced with dyslexia to become a teacher. She described using similar strategies to support her daughter Rachel when she was diagnosed with dyslexia and Asperger's. It appeared from her narrative that Kate had a strong belief in her ability to overcome challenges.

Rachel Perrin

Rachael appeared to share her parents' view on the importance of family. She seemed to have close connections with her parents and her grandparents, with regular and frequent contact being the norm in their relationship. Indeed she lived close to her parents at the time of the research. Even when she was at university, Rachel described returning home frequently and having regular contact. She felt that being at home or near her family was particularly important for her and that being with family made her feel safe because of her Asperger's.

In describing her father, Rachel seemed to affirm much of her mother's narrative about her father and his qualities. She described being very close to her father, suggesting that she had always been a 'daddy's girl'. This did not however appear to preclude a close relationship with her mother. Indeed Rachel was working full time alongside Kate at the time of the research and also described plans they had considered with her sister, to set up a business together.

Rena and Dave

Both Rena and Dave also suggested that family relationships were close and connected, with regular and frequent contact being the norm. Nevertheless,

as parents they suggested it was important to respect their children's right to lead independent lives. This seemed to reflect a belief in non-interference, but involvement when help was requested. Rena in particular confirmed Kate's assertion that as a family, they have worked things out together and openly communicated, even on difficult issues. She further suggested that although it's likely that any conflict in the family would have been between her and Kate, because they are very alike, they generally worked it out together.

They appeared to know Kate well and described her as being a strong person who made her own decisions. They suggested that she has always been committed to her family, but also has taken on a lot of other commitments, sometimes to her detriment. Rena and Dave also appeared to have a strong connection to Alistair and described him as a really nice guy. They seemed to feel that he was an important part of their lives as a family and valued the contributions he made, including having been a good provider for his children.

Interview Context

My initial contact for participation in the research was with Kate and then Rachel. During our discussions to explore their perspectives on participating, I discussed with Kate whether it would be possible for her to approach Alistair and other family members about the research. Kate agreed to approach Alistair and also to discuss the research with her parents and her other daughter. Ultimately, five members of the family participated, Alistair and Kate, Rachel, Rena and Dave. The family participated for all three time points, over a period of 20 months. A total of 13 interviews were completed, with Kate and Alistair taking part in five interviews; Kate and Rachel in one interview; Kate on her own in one interview; Rachel in a further two interviews; and Rena and Dave were interviewed apart on the first occasion and then together for the final two time points.

Interviews were conducted with each of the family members in their homes, at their request. I first met Kate and Rachel at Alistair and Kate's home. Alistair and Kate had been undertaking extensive remodelling of their home

when I visited on the first occasion and this continued to be the case until May 2013. Their daughter Rachel was living next door to Alistair and Kate, with her partner Mike. Rena and Dave lived 3 miles away.

My initial contact with Kate had reminded me that I had previously had contact with them when volunteering for the Alz Café that they attended. Kate seemed to feel that this would be beneficial because Alistair did not feel comfortable with strangers and may therefore otherwise have been reluctant to meet with me to discuss participation. I subsequently met with Alistair and Kate at their home and Alistair did appear to recognise me and seemed happy to discuss the research. We explored his involvement in the research and he appeared able to give informed consent. As with the other people living with bvFTD, I continued to explore his understanding and willingness to participate throughout the time they were involved in the research. This was particularly significant because I changed my work role midway through the research to a role in which I was to have direct contact with them in a service development context. I therefore needed to ensure that Alistair understood in what context I was seeing him and was able to continue to make an informed choice about his participation.

As can be seen from the family narrative, a strong feature of their interviews was their closeness and connectedness. This was the largest number of family members from one family that I had been able to recruit. While this was beneficial in terms of developing a rich and in-depth understanding of their family life, it also presented challenges in terms of the level of immersion in their lives that I experienced both during the research and subsequently during analysis. I was particularly aware of this because they seemed to be an articulate and communicative family and also that I experienced an emotional connection with them. I found this connection to be particularly significant with Alistair and Kate as I also had contact with them within my work role. There were inevitably risks associated with this immersion. The risks included becoming ‘over involved in their lives’; allowing their perspective to dominate the final results of analysis and because

connectedness seemed to be the dominant narrative, it felt difficult to see beyond this in my analysis.

In recognising this risk of over involvement, I was aware of the need to use personal and research supervision to reflect upon my relationship with the family. During the early part of my involvement with them, just after I changed my work role, Kate invited me to their celebration of the completion of their work on the house, which occurred two days after Rachel's wedding. I discussed with my supervisors whether I should attend. I felt that to refuse could cause offense and as I was asking a lot from them in committing their time to my research, I needed to consider if a refusal would be disrespectful. I also recognised that this made me feel uncomfortable and in my practitioner role, I would not have considered that it would be appropriate to attend. After some discussion I decided to attend, but explained that I would not be able to stay for long.

On reflection, I recognised that it wasn't right for me to attend, particularly when I was asked who I was by friends of Kate and Alistair. While it seemed important to Kate that I had attended, this caused me to reflect upon my boundaries in the research generally and particularly with Kate, who I had come to recognise had vulnerabilities despite her apparent strength of character. I also wondered if Rachel, Rena and Dave had not been told that I had been invited as they seemed surprised at my presence. I therefore left as soon as it was possible to do so.

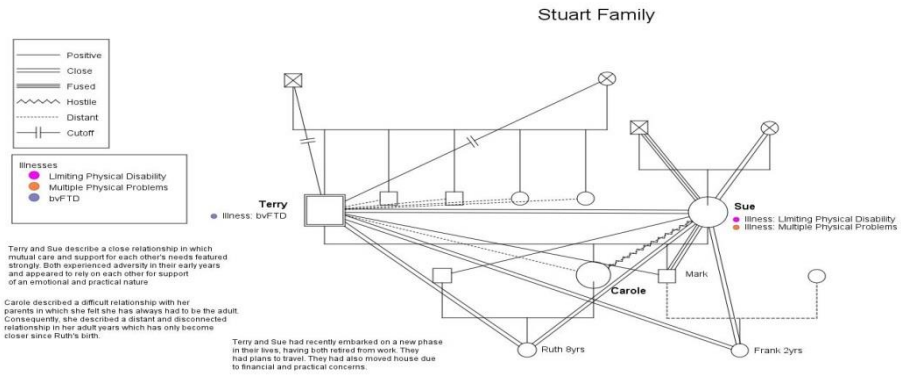
I reflected in supervision upon my boundaries and motivation for attending. I also considered what Kate might have wanted from the relationship and what she might need. At the end of my next research interview with Kate, I explored what her support needs might be, as it seemed to me that her feelings of loss and grief at the changes in Alistair were very challenging for her and that she didn't appear to have any source of support for herself. I wondered whether the research relationship addressed some of these needs, albeit indirectly. Having considered this, I met with Kate and arranged to provide her with information about sources of support at her request.

Considering how I managed their data within the analysis also proved to be challenging. The risks involved in portraying an uncritical view and allowing those within the family who were most articulate to dominate was an issue I needed to consider. It was therefore important that I gave equal credence to quieter voices, for example enabling Alistair and Dave's voices to be heard in the interviews and then subsequently in the analysis. For example, where I was aware that Kate had dominated in a response to a particular issue, I would specifically address this topic with Alistair when involved in interviews with them as a couple. This was respected by Kate and Alistair had the space to give his own perspective. In discussion with my supervisors, I also recognised the need to foreground the voices of those who were less likely to be heard when carrying out analysis. It was also important to be open to potential expression of difficulties within their relationships. Even though these perspectives may be expressed with a 'quieter voice' it was important to highlight the complexity of their experience rather than presenting a one-dimensional view.

6.8 Stuart Family

The Stuart Family are a 3 generation family comprising of:

Terry (aged 65, living with FTD)	Liam husband to Carole
Sue (aged 66) Wife of Terry	Ruth (aged 7) Carole and Liam's daughter
Carole (35) daughter	Freddie (aged 2) Mark's son
Mark son	Bob (Brother to Terry)



The Family Relational History: Individual stories, together but separate

Terry and Sue Stuart

Terry and Sue have been married for 38 years. They discussed their respective families of origin and the circumstances in which they met and married. Both Terry and Sue appeared to have experienced adversity in their early lives. Sue explained that she had been born with a significant disability and they both seemed to suggest that Terry had experienced difficult relationships with his parents. Sue seemed to feel that their respective experiences had impacted upon the way in which their relationship was received by her family. She explained that even before they were married she had become involved in practically supporting Terry due to his difficult family relationships, for example doing his washing. However, this was not welcomed by her mother. Sue suggested that her mother had wanted her to marry someone who would look after her because of her disability and that as a consequence, she was not happy about their relationship. Nevertheless, Sue and Terry described her father as having given them a lovely wedding and also seemed to feel that her father had been more accepting of Terry. In spite of her mother's resistance to their relationship, Sue appeared to feel that they had succeeded in their lives together and that she had achieved the things she had wanted, but not thought possible, including children and a career. Sue seemed to feel that caring and being cared for was an important aspect of their relationship.

Sue's perspective appeared to dominate this discussion, however Terry seemed to indicate his agreement with her narrative, often briefly commenting on or affirming some of the things that she had said. Terry also appeared to affirm Sue's narrative about his family. Furthermore, he seemed disconnected from them, expressing anger towards his parents and some of his siblings. Their early life experiences appeared important in understanding the context of their relationship.

Sue's health and care needs as a consequence of her disability, also appeared to have been an influence on their married life together. Sue

described having a life threatening condition when their children were teenagers. In recent years she described experiencing chronic pain, restricted mobility and other difficulties associated with her disability and the after effects of the life threatening condition. Thus she needed support and assistance herself. She explained that she had recently needed Terry's help and assistance more and more due to her unsteadiness which appeared to affect many aspects of their daily lives, including shopping and similar activities. Furthermore, she described being unable to drive due to the restricted mobility she experiences. It seemed therefore that Sue had held expectations of Terry in regard to help and assistance throughout their married life and that these expectations had increased as her support needs had become greater in recent years.

When discussing their relationship, they appeared to feel that they had pulled together for the benefit of themselves and their family and had coped through difficult times, including redundancy for Terry. They seemed to feel that they had been close, although this closeness was tested by changes in intimacy, which appeared to have been associated with diabetes. However despite the difficulties they had experienced, Terry and Sue suggested that they had rarely argued.

In 2008, both Terry and Sue described making the decision to retire. Sue suggested that she was experiencing increasing difficulties with her health and Terry had indicated that he felt that it was the right time for him too. At around the same time, they suggested that they had also made a decision to move home which appeared to be driven by financial reasons and to be nearer Carole. They moved in July 2009. Their son Mark moved out of the family home at the same time. They appeared to have made plans about how to spend their retirement, including travelling to different places in the UK. It therefore seemed as though they were looking forward to a new chapter in their life together.

In describing who was in their immediate family, they identified their two children, their children's partners and their two grandchildren. Terry appeared

particularly animated when talking about his grandson (Mark's son) who was two years old at the time of the first interview. They described regular telephone contact with both children, although they suggested this was more frequent with their son Mark.

Both Sue and Terry acknowledged that their children lived very busy lives with work and children, consequently regular visits were difficult to achieve. Furthermore, as indicated above, their son lived some distance away and as a consequence of Sue's disability, travel was difficult. Nevertheless, they appeared to feel that they were close to their children and as indicated above, explained that one of the reasons for moving was to be closer to their daughter Carole. Indeed they suggested that they had involved both children in their decision making around moving home. While acknowledging their closeness to both children, Sue identified feeling a particularly close bond with their son Mark, who had lived at home until they had moved in 2009. Sue and Terry seemed to feel that this was because of his likeness to her father whom she was very close to. It appeared that although Sue's father had died in 1998, she still seemed to struggle with her grief at his loss.

Sue and Terry indicated that there were some friends from their previous area that they had kept in contact with and Sue identified siblings that she continued to be close with. Nevertheless, their perception of family seemed largely to revolve around their children and grandchildren.

Carole

Carole described a lack of closeness with her family and a difficult relationship with both of her parents and her brother. She suggested that her mother was the more dominant of her parents, was in charge and made most of the decisions. She also believed that she and her mother had experienced conflict in their relationship in her teenage years because her mother was very strong minded.

However despite this, Carole felt that she had always had to be the adult in the relationship with her mother from an early age. She suggested that this

had impacted upon her relationship with her Mum, indicating that as a consequence she had not felt able to share aspects of her own life with her. Furthermore, she described a lack of closeness with her father, suggesting that although early in her life she had been a Daddy's girl, that this had changed and that she felt her Dad had not really engaged in family life. She also suggested that her mother had favoured her brother over her and that her brother had been selfish. Carole had left home when she was 19. She felt that the lack of closeness with her family continued into her adult life and that her parents had not cared about her in the same way that they had cared for her brother. She suggested that her brother had a better relationship with them, because he had lived at home until he was 31, whereas she had felt distant from them. She appeared to feel that they had not really been motivated to be a part of her life.

Carole described a shift in relationships in recent years, brought about by the birth of her daughter and her own need to understand more about her relationship with her parents. She suggested that the arrival of Ruth had given them some common ground; consequently, they appeared to have been able to build a different relationship. It also seemed that Ruth's arrival heralded a new opportunity for Terry and Carole was able to see a different side to her father and appeared to value his relationship with her daughter. Carole therefore described feeling closer to her parents now, but recognised that it had taken effort on both sides to achieve this.

It appeared though that Carole's relationship continued to be primarily with her mother. She suggested that her mother was the one she had most contact with now. However, in spite of the change in their relationship, Carole continued to believe that she had to parent her mother, which seemed to be demonstrated in her perspective about their future needs. She indicated that she believed that she would be the one who ended up caring for her parents. However, this was not something Carole welcomed, indeed there seemed to be some ambivalence about the possibility that she would become a carer. Therefore while Carole described some closeness, there also appeared to be some evidence of her imposing a limit to her contact with them. She

suggested that this was because of the many demands on her life, although it seemed that this may also be because of the sense of responsibility she felt for them.

Interview Context

My initial contact with this family was with Terry and Sue. I explored their participation and the possible participation of other family members. Terry and Sue were happy to participate and subsequently had discussed the research with their two children. Ultimately, Terry, Sue and Carole consented to participate. Terry seemed to comprehend the nature of the research and described having a family member who had undertaken a PhD. I explored consent on an ongoing basis with Terry, to ensure that he was able to make an informed choice at each time point.

The family participated in all three time points and a total of 6 interviews were completed over a period of 19 months. I interviewed Terry and Sue at their home and interviews were conducted together. Carole chose to be interviewed separately at her home, some 10 miles away from her parents. Terry and Sue were aware that she was participating.

In working with this family and in particular Terry and Sue, I was particularly reminded of the power that I held as a researcher when interviewing people with dementia and their family members. As indicated above, Terry appeared able to demonstrate his knowledge of the research; that he could stop at any time and the boundaries of his participation. He consented to participate and I felt that he understood what we would be doing together and what this would be used for. Indeed he mentioned that a family member had undertaken a PhD, so seemed to understand the context in which I was asking for their participation. We commenced the interview and began by talking about their family relationships. I had previously explained that my purpose in doing this was to understand their ways of being as a family. During this discussion, Sue raised personal experiences from Terry's early family life, following which he talked about these at some length.

Following the interview, as agreed with Terry and Sue, I sent through a transcript of the interview. When I contacted them to arrange a further appointment to discuss the transcripts, Terry appeared upset by the transcript. He said that I had got things wrong and he wasn't at all happy with what was in the transcript. On meeting with them, he again reinforced his concern about the transcript and I felt that one of his concerns might be about his discussion of his family and their history. I emphasised that it was not necessary for me to keep this information in the transcript, that I could remove it if he wanted me to, which he did. I asked them if they wanted to continue with the research, they insisted that they did and Terry seemed much calmer after our discussions about what to change in the transcript. However, he in particular, told me that he didn't want to see the transcripts again.

This interview caused me to consider what impact my questioning style may have had on Terry's revelations of his past and how sharing the transcripts may have influenced this. I reviewed my questions and the recording and explored this event within supervision. Although Terry did not seem anxious, upset or indeed hesitant when talking to me about his experiences, it concerned me that he had revealed so much of his 'vulnerable self'. This caused me to reflect on what I should do with this information and why he might have done it. I had concerns about the possible implications for Terry of sharing such information and whether he required support with this. We reviewed the ways that he had managed to cope with these experiences at the end of the interview and in response, he and his wife described various coping strategies and ways of managing the impact on his life. Clearly, I cannot be certain of Terry's reasons for sharing this information with me; however my discomfort prompted me to recognise that it was important to see this as an ethical moment which I needed to address.

It seems possible that the impact of bvFTD may have influenced how much he revealed about himself and I wondered therefore whether he would have chosen to share these experiences had he not had bvFTD. As bvFTD impacts upon the capacity for abstract thinking, questions which invite open

discussion may have prompted Terry to offer greater detail than he would have normally. While I had prepared carefully to support the involvement of people with dementia, including setting the context of the interview, this may have had an adverse effect for Terry. In particular, I recognised that while open questions are an important feature of qualitative interviewing, their use may make it difficult for a person with bvFTD to understand the scope of the interviews. Therefore I reflected upon the need to use questions which are clearer, specific and concrete, as these are likely to be more successful, as is the preparedness to rephrase these questions to ensure they are understood.

A further area for consideration came in my interviews with Carole. At the second time point interview, Carole had raised that her father had asked her what she had said. This combined with Terry's reaction to the transcript at the first time point, highlighted the possibility that Terry had concerns about how others viewed him and that he may be trying to manage what I thought about him. Furthermore, given Carole's difficult relationship with her parents, I recognised that she may be concerned that her parents might hear what she had said. I reinforced the boundaries of confidentiality with her and she seemed reassured by this. However I was aware that Terry's review of the transcript may also have influenced his self-concept as it was evident during my discussions with Terry and Sue that there was some conflict between them concerning the impact of bvFTD and that Terry on occasions was quite upset at Sue's perspective. Having considered this in supervision, I offered Terry and Sue the opportunity to be interviewed separately although they chose to continue to be interviewed together. I also respected Terry's request not to review the transcripts again.

6.9 Chapter Summary

In this chapter, I have documented the relational history of each of the seven families that participated in the research. These summaries are reinforced by fuller descriptions which are supported by participant quotes (see CD appendix 21). In keeping with narrative analysis, these storylines are presented individually, in order that the reader may understand the family context in which the experience of bvFTD is grounded. Each family

experiences a relational history that is unique to them, as a whole family, between generations and as individuals. It is important to note that the recounting of the relational history differs between participants within the same family, particularly when comparing the contributions of the family member living with bvFTD and their other family members. While it is inevitable that different perspectives will be present, it is necessary to acknowledge that the impact of bvFTD may have made it difficult for those participants to contribute fully to the recounting of their family relationships. While the family storylines point to the uniqueness of each family, it nevertheless seems that relationships within and between these 7 families exist on a continuum from **cohesive and connected ---- disconnected and distant.** One of the possible challenges of research such as this is that recruitment of families with conflictual or distant relationships seems more problematic and their perspectives have been less in evidence in qualitative studies exploring the impact of dementia upon relationships (La Fontaine and Oyebode 2014). It appears that the 7 families in this study represent a range of relationships on this continuum and therefore provide the basis upon which the impact of bvFTD on diverse family relationships can be considered.

Furthermore, in this chapter I have summarised my experience of interviewing each of the families and in doing so have provided an account of the factors influencing the research process, including my own influence as a researcher. I have considered the boundaries of researcher participant relationships, as well as the interface between the multiple identities I hold including those of researcher and nurse practitioner. I have also considered some of the environmental and familial factors influencing initial participation and ongoing involvement in the research. This has highlighted that ongoing reflection and supervision have been critical to an ‘ethically mindful’ approach to undertaking sensitive research such as this (Warin 2011; Bowtell et al. 2013; Brown-Wilson 2011; Hoskins and White 2013).

Chapter Seven: Challenges experienced over time by we / I, brought about by behavioural variant frontotemporal dementia (bvFTD)

7.1 Introduction

In the previous chapter, I have provided a 'picture' of each of the seven families view of their relationships prior to the experience of bvFTD. These relationships range on a continuum of **cohesive and connected --- disconnected and distant**. In this chapter I present the results of a grounded theory analysis which describes a series of psycho-social, cognitive, behavioural and relational challenges. These challenges represent different aspects of the experience of bvFTD for these families and for individuals within the family, including the person with bvFTD. Furthermore, there are a number of elements that impact on the experience of these challenges and the coping processes used by families and individuals within the families. These elements are also described.

I have identified four challenges. Two of these relate to the experience for the whole family, including the person with bvFTD; **awareness and understanding of the changes** and **managing everyday life.** A further challenge relates directly to the experience of living with bvFTD for the person with dementia; **being me in the context of bvFTD.** A final challenge relates specifically to partners or adult children who are living with or heavily involved in supporting the person with bvFTD; **we're not the same anymore.** Table 7.1 outlines these challenges and the issues influencing them. The challenges experienced by individuals and families and the resulting coping processes are multifaceted and complex. Furthermore they appear to have a reciprocal influence on each other. Thus a challenge for some may arise from a coping process used by others. For example, the experience of 'being me' in the context of bvFTD (for the person with dementia) may be significantly influenced by the strategies that are used by family members to manage everyday life, including enabling and facilitating, or minimising, denying and distancing themselves from the person's experience of the world. Thus in presenting this data there are inevitably

close connections between sections in this chapter and between this and other chapters.

Furthermore, where influencing elements are relevant to more than one of the challenges, I have summarised their influence in subsequent challenges, although any specific additional factors are also addressed as required.

Table 7.1 Challenges experienced by we/ I

Challenges	Subthemes	Influencing Elements
• **Awareness and understanding of the changes**	• Noticing changes/ explaining changes • Its dementia; moving from awareness to understanding • Awareness and understanding within the wider family • Awareness and understanding over time	• Emotional and physical proximity • It's really subtle and difficult for others to see • Readiness to see and hear the changes • Prior relationship • Availability of knowledgeable and supportive professionals • Understanding of bvFTD
• **Managing everyday life**	• Changes in cognition • Changes in mood • Changes in emotional and social behaviour • Co-ordination • Managing everyday roles • Managing self-care • Motivation	• Availability of knowledgeable and supportive professionals • Accepting – resisting— rejecting • Awareness – Unawareness • It's really subtle and difficult for others to see • Past experiences of similar difficulties • Peer support • Prior relationship
• **We're not the same anymore / I'm not the same anymore**	• You're not the same so we're not the same anymore a. You're not the person you were to me b. We're not the same anymore	• Awareness – Unawareness • It's really subtle and difficult for others to see • Living together by choice • Prior relationship
• **Being me in the context of bvFTD**	• You're not the same anymore • I know I'm changing --- I've not changed at all • I need to be in control • I need to feel safe and secure	• In step or out of step in our awareness of changes • Family coping processes • I trust my family's ways of supporting me • Sense of self • The impact of bvFTD on social and cognitive functioning • An important person in our lives --- he was just there really • Understanding their emotional world

7.2 Awareness and Understanding of the Changes

Becoming aware of and developing an understanding of bvFTD and its impact seemed to be a critical component of family functioning. The challenge of *being aware* of the changes brought about by bvFTD began when symptoms first became apparent and continued beyond diagnosis. It seemed that those closest to the person with bvFTD noticed changes first and in some families this was followed by the person with bvFTD. Other, wider family members' awareness seemed to come at a later point. Differences in awareness of the changes could be a source of difficulty within the families. This theme was present for all seven families who participated. Narrative excerpts from all three time points contributed to this theme with three subthemes emerging from analysis;

- Noticing changes/ explaining changes
- It's dementia; moving from awareness to understanding
- Awareness and understanding within the wider family

Noticing Changes / Explaining Changes

The time before diagnosis began with a gradual realisation that changes were occurring. Those closest to the person with bvFTD and sometimes the person with early symptoms were most likely to recognise these changes. Initial symptoms were described by closest family members, such as difficulty with work, with managing complex and everyday tasks and changes in mood and personality. For example, Mollie experienced a gradual recognition that Anthony was changing in mood and in his ability to manage everyday tasks:

> *Mollie* *But I think what I really noticed was when, I think it was when you were coming home and things like this, with the showering and things. He was becoming more withdrawn, a lot of withdrawn, deep thought; always in deep thought and thinking. […]*
> *It got to the stage where he couldn't remember how to use certain things we'd had for years, things like the microwave and the shower. […] [T1]*

Although not at the same pace as Mollie, Anthony also developed a gradual awareness that he was not functioning as well as he had previously (Table 7.2):

Table 7.2: developing a gradual awareness	
Anthony	*But then some things you just couldn't remember doing. If I was taking the wheels off anything you get the wheel brace out the back of the van and the wheel brace stays there until you've tightened them all up, then the wheel brace goes in the back of the van; so very methodical and always aware what we're doing. And I could go round and tighten all the wheel nuts, I've got the wheel brace in my hand and not an inkling whether or not I've tightened the wheel nuts or not. So, you go round and check them all again and yeah, every single one tight. You go to throw the wheel brace in the back of the van, "Did I tighten the wheel nuts up?" Not a clue. So, you go round again and you still can't remember doing it. So, I'd then go in the office, get hold of one of the drivers, "Come here, stand there and watch me tighten up these wheel nuts" and tightened all the wheel nuts up. "I've tightened the wheel nuts up, haven't I? They're all tight?" [T1]*

However, initially a range of alternative explanations for symptoms were found for many of the participants, as most did not appear to consider that it might be dementia. Some families seemed to attribute early symptoms to changing life circumstances such as changes in employment or stressful life events. For example, Phil explained that initially he had thought that the changes were related to Penny leaving work:

> *Phil* *And I said when she'd resigned her position, it was like somebody flicked a switch and she switched off. But of course it was nothing to do with that really. It was the onset of this illness. I think. [T1]*

It also appeared that some spouses had thought that these changes may have been indicative of a desire to end the marriage, as Kate described below:

Kate *I just thought he couldn't be bothered anymore and that, you know, he was looking for a way out. [T1]*

Indeed three of the spouses described an increase in conflict with their husbands prior to diagnosis, which may have given rise to fears about a breakdown in their relationship.

One family felt that the changes represented exaggerated aspects of existing personality traits. For example, Pamela Hugh suggested that Elizabeth had always been self-serving**:**

Jenny *So what has she always been like and what's different now from what she used to be like?*

Pamela *Well I think that she's always been selfish, she's always wanted her own way… [T1]*

Thus it may be that early changes are subtle and therefore interpreted as usual for that person. More general assumptions about human behaviour may also influence explanations of symptoms. For example, memory difficulties raised by Elizabeth's husband were attributed to ageing:

Pamela *Her husband was saying, "Oh your mum's memory's terrible." And we didn't take any notice because in your 70s well that's age isn't it? Well this is what we thought; this is what we were hoping. [T1]*

While those closest to the person with bvFTD and on occasions, the person with dementia experienced an increasing recognition that changes were occurring, it seemed that this developed at a different pace for extended family members. Family members who had infrequent contact and/ or who were less emotionally close appeared to have less awareness prior to diagnosis. For example, Anthony and Mollie Burton appeared to have an increasing awareness that things weren't right. However, they felt that others in the family did not notice the changes because they weren't in regular contact or close to Anthony:

Jenny *Did your children notice there were changes? Was there anything that they picked up on?*

Anthony *We don't see them frequently enough for them to notice really. And also when you do visit them you are not your usual self: you go there and you have a conversation with them or whatever; and they're only short visits. [T1]*

Anthony's daughter, Jane, seemed to confirm this, suggesting that because they didn't meet regularly, she had not noticed as much change:

Jenny *Were there other things that you noticed?*

Jane *Not a great deal, no. But I think it's probably because I didn't spend so much time with him. No. [T1]*

Other families also experienced variability in awareness and in some this difference in perspective had the potential to create tension in relationships. For example, Sarah and Alex Lewin reflected on the challenge their different levels of awareness had caused, suggesting that some conflict may have arisen because of these different perspectives:

Sarah *His sister and brother-in-law came yesterday and you wouldn't think there was anything wrong with him, nothing whatsoever.*

Alex *No, that's why we find it difficult I think with some of the family members: they don't believe he's got it. And we say, 'You don't live with what we see and hear.' And I've had a chat with his sister here, […] and she said, 'I don't think he's got dementia.' And I said, 'You don't see it.' [T1]*

It seemed therefore that awareness was variable within these seven families. However, with a growing recognition of changes in behaviour and personality, engagement with the difficulties and their consequences became necessary for close family members and in some families, the person with bvFTD. For some, the decision to seek help arose from a critical event surrounding the person's behaviour. For example, in the Hugh family, the death of Elizabeth's husband served to bring them into closer contact with Elizabeth which highlighted increasing risk taking (table 7.3):

Table 7.3: Increased risk taking	
Pamela	*Yes so I drove the car and followed her home and she got to the traffic lights in [local area] and jumped a red light.*
Jenny	*Right*
Pamela	*So I sat in my car thinking shall I watch or shall I close my eyes and wait for the crash ((laughingly)). Anyway she got home and I said, "Do you realise you jumped a red light?" And she said, "Doesn't everybody?" So after that she'd bought all this meat from the butcher's and she said, "Oh I'll put it away later," well she didn't she just left it out, she didn't put it away, she didn't put it in the fridge or the freezer and she'd left food in the back of the car and when they came to section her then they opened the boot of the car and there was just these bottles because when she had staff they were reporting that she was going out to the car at regular intervals and she was going out to the car to swig whisky. [T1]*

In one family, help seeking also appeared to have arisen from a process of discussion between family members about the changes they noticed. For example, Melinda described discussions with their adult children:

> *Melinda* *And we'd lost him in the garden centre and we couldn't find him, it took hours to find him, because he'd wandered off. And then when we thought about it and we were talking as a family, we said, 'Remember when we went to such and such and he just didn't know where he was?' and things began to piece together. [T1]*

These family conversations also included Bert, who lives with bvFTD, who appeared to have accepted that they needed to seek help as in this quote, where he acknowledged that he needed to go to the doctors because he knew something was wrong:

> *Jenny* *So that was a worry for you, that Melinda wouldn't stay with you.*
>
> *Bert* *Well, yeah, because that was one of the reasons why in my mind we went to the doctors in the first place with what was*

happening. Because I knew, I felt there was something wrong, didn't know what it was, […] [T2]

Initially help was sought from the person's general practitioner, with referrals subsequently being made to specialist services, including mental health services. Some families experienced lengthy delays in this process. Furthermore, participating families received variable levels of support and information from professionals about the diagnosis when this was eventually made. The diagnosis was shared with the person with bvFTD and the family member who was present during the diagnostic process. None of the extended family members were directly involved in the diagnostic process.

While the diagnosis provided answers and for some a sense of relief, a number of the close family members, including the person with bvFTD, reflected on the distress they experienced afterwards. For example Anthony had explained that he expected to be diagnosed with dementia but when it came he described feeling devastated:

Mollie *((Anthony)) was glad he'd got his diagnosis, but it really did knock you for six, didn't it love, for a couple of months.*

Anthony *Yeah, which was totally unexpected. I couldn't explain why on earth it did affect us like that. [T1]*

Mollie reflected upon her own difficulty adjusting too and described becoming over-protective of Anthony as a consequence. Kate also described her distress at having to tell her children and grandchildren.

It's dementia, moving from awareness to understanding?

Awareness within families continued to be variable following diagnosis and appeared strongest in those who were in closest contact with the person with bvFTD. Four of the spouses viewed the diagnosis as an opportunity to understand what was happening and therefore how to support the person with bvFTD. For example, Kate described the importance of diagnosis as a route to understanding:

Kate *Understanding it, yeah. Once we knew what we were dealing with we were all better able to cope. It was the not knowing, it was those three years of not knowing what was happening to this man and trying to guess all the time. But actually, once we got the diagnosis and we could find out that actually he wasn't abnormal. Okay, he wasn't doing Alistair things, he was doing strange things, but they weren't abnormal for somebody with frontal temporal dementia. […] and once we could start putting things into sensible boxes, we could better manage it. [T1]*

Furthermore, the Perrin and Morris families appeared to support the development of understanding within their whole family in order to achieve this:

Melinda *So, it's kind of adapting – we're slowly learning – and supporting each other, how to adapt. […] [T1]*

While some families sought to understand the nature of the changes and the impact these had on the person with bvFTD, it seemed that this did not always follow after diagnosis. In three of the families, those directly involved in caregiving appeared to have difficulty recognising how bvFTD might affect the person throughout the research. For example, even though Pamela and Jonathan seemed aware that Elizabeth had difficulty with planning, processing and memory, they didn't connect these difficulties with her mother's behaviour.

Jonathan *I mean she's done strange things, we were around at her house, Pamela had told me that she'd cut a pull-down blind in her conservatory, a white pull-down blind she's cut it… […] And I said, "Why did you do that?" "Oh I don't know." So I don't know whether she really couldn't remember or whether she really didn't know that she was doing it at the time or whether she didn't want to say, but that was very peculiar, that was almost inexplicable why anybody should do that. […] ((laughs)). [T3]*

An apparent consequence of this lack of understanding appeared to be conflict within relationships as described in the quote below (table 7.4)

Table 7.4: Lack of understanding

Sue	*I'll tell you what he did, because I find it hard to do some aspects of my cleaning and I said "This shower needs cleaning.", because it's just, doing the tiles, I can't stretch up. So I said "Would you do it for me?" and I was doing some ironing and I left him. I said "I'm not going to interfere, you don't like me interfering." And I had all of the things for what it's needed and other things. And he was squirting the bathroom cleaner on the tiles with this grouting brush, but no water. And he says to me "This cleaner has fumes. And he said "Now I've just squirted it and then wiped it with another cloth." First of all he starts cleaning the...*
Terry	*I'm not a domestic.*
Sue	*No, but since we've been here you have done it numerous times. But he just completely forgot how he'd got to do it.*
Jenny	*So it's sometimes quite difficult to work out how to do things.*
Terry	*Mm.*
Sue	*And so of course I had to do it myself. […] So he shouts at me. "Oh, I'm useless." and all this. I said "Why didn't you ask me if you weren't sure how to do it?" I said "I just didn't want to keep coming in, you tell me off. 'Can't I do anything on my own?' and all this." This is what it's doing to us. I'm trying to motivate him to do something, but he makes such a mess of doing something and I think "I might as well do it myself."*
Jenny	*So it causes a bit of conflict.*
Terry	*Mm.*
Sue	*Yeah. We've never, have we, with all the years we've been married, we've never really rowed. We might have just had a slight difference of opinion every now and again. […] And like I said, I don't like being shouted at so it's very hard. How do you... just let him get on with it?*
Jenny	*How does that feel for you when you have cross words? What's that like?*
Sue	*I don't think he really knows he's doing it, do you?*
Terry	*I just say "Four across. Four letters."*
Sue	*[…] Do you see what I mean? But I remember him saying it. [T2]*

The arguments that Sue described may have arisen in part because of Sue's lack of understanding of the effect of bvFTD on Terry's ability to process and sequence. Consequently, she appeared unable to support him and positioned him as at fault because he couldn't successfully achieve the task

in hand. Therefore, differences in understanding were likely to impact upon ways of managing the impact of bvFTD and to have consequences for relationships.

Awareness and understanding within the wider family following diagnosis

As described earlier, in some of the participating families, those in the wider family network were less aware at diagnosis. Differences in level of awareness and understanding continued following diagnosis. For example, in the Perrin family, Dave and Rena experienced a lower level of awareness than their daughter Kate or granddaughter Rachel. Rena appeared to feel that this was because they were 'on the fringe' of things:

> *Rena* *And people say things like, "Well we were with him last week and there's nothing wrong with him." And of course there isn't because you don't see him getting… They don't notice the difference between when he's suddenly can't cope and things. And I realised then that we're just on the fringe really we don't…we can't really understand how hard it is for them. [T1]*

However by time point three, both Rena and Dave had a greater appreciation of the difficulties that Alistair was experiencing:

> *Jenny* *So tell me about what sorts of things you've noticed have changed.*
>
> *Rena* *He's not as good at making a decision. And he's very quickly agitated. Since the building work finished in the spring, I think there's been a deterioration.*
>
> *Dave* *Put it this way. I have to slow him down now a little bit more than I did before. He can be quite when I say rough... He doesn't have the patience he did have.*
>
> *Rena* *Bit of bull at a gate, isn't it. And then if it doesn't go right he gets very stressed. [T3]*

Thus while some family members may have lesser awareness and understanding at diagnosis, over time this seemed to increase. However,

despite awareness, some wider family members appeared to deny the changes. For example, Mollie discussed her daughter's apparent lack of understanding (Table 7.5):

Table 7.5: Lack of understanding in wider family

Jenny	*[…] So have the relationships that you have…*
Mollie	*They've deteriorated since Anthony's been ill. That's being truthful isn't it?*
Anthony	*Yeah.*
Mollie	*That's being…I'm just being…we went on holiday with my daughter, […] but it seemed to annoy her so much that she could not believe how much I actually did for Anthony. She said, "It's like having another child." […] She said, "You've got to remind him to have a wash, you're reminding him to come and sit and have your breakfast and do this, do this. […] She said, "I couldn't believe it," she said it was like having another child. She said, "Oh rather you than me," she was quite annoyed about it all wasn't she because I couldn't go to do different things with the children because obviously the noise and certain things. We did, we took them off to do different things didn't we with Chloe and Isla? But it was difficult and if I could have come home after four or five days ((laughingly)) I would have done. It was awful. We were on eggshells. […] [T2]*

She appeared to feel that her daughter did not want to understand because it meant the activities they engaged in with the grandchildren were restricted. Her quote also suggested that differences in understanding and awareness within the family had the potential to create distance and disconnectedness in family relationships. However, some families were able to acknowledge the reasons for this difference in awareness and make allowances for it:

Melinda *But he finds the difference in his dad; out of all of them, Adam finds that difference in you the hardest to cope with, doesn't he? […] Adam can't really understand those changes, where all the others, […] they kind of accept that and can adjust their mood to yours. I think with Adam,*

he's got his dad up on a plateau, hasn't he, so he's the one that's struggling, he's the one that we've got concerns about. [T1]

Awareness and understanding with progression of bvFTD

Differences in levels of awareness and understanding were further complicated by the progressive nature of bvFTD. It appeared that this created a cyclical process of awareness and understanding. For example, Alistair and Kate reflected on their experience of the realisation that there were new changes (Table 7.6):

Table 7.6: A cyclical process of awareness and understanding

Kate	*To him the scary thing was realising how the disease, how the illness is...*
Alistair	*Hitting.*
Kate	*Yes. […]*
Alistair	*I'm trying to sort of say well that's how I was, this is how I am now, how much has changed. Trying to collate the two and that is the frightening scary part. You think, well I used to be able to do that, why can't I do that now. I don't feel any different in myself, but... and it's just... that's the scary bit, when people... yeah...*
Kate	*Point out.*
Alistair	*Point out the difference or notice the difference and then you think oh, that's not right. [T1]*

Therefore each new change brought an increased awareness that bvFTD was progressing, which in turn required a new level of understanding. It seems likely that all of the families experienced repeated patterns of increasing awareness and understanding as bvFTD progressed and may have been regularly 'out of step' with each other as a consequence.

Thus awareness and understanding of bvFTD is variable within families and occurs at a different pace for those closest to the person with bvFTD when compared with those who have less frequent contact and/ or who are not as emotionally close. Furthermore, there are some who deny that changes are taking place or have not been able to make the transition from awareness to

understanding. Some families appear to have been able to work together to understand what is needed whereas it appears that for others a lack of a shared understanding has caused distance and disconnectedness in relationships.

7.3 Influencing Elements

A range of elements would appear to influence this theme. These include:

- Awareness of the person with bvFTD
- Emotional and physical proximity
- It's really subtle and difficult for others to see
- Readiness to see and hear the changes
- Prior relationship
- Availability of knowledgeable and supportive professionals

It appeared that the level of awareness of the person with bvFTD may also influence the awareness of family members. The awareness of the person with bvFTD is addressed later in this chapter under the theme, **Being me in the context of bvFTD**. However, their awareness, even if it is not entirely congruent with other family members may provide the opportunity to discuss and consider the changes occurring as described above (p.143-4, Melinda and Bert).

As discussed earlier, the emotional and/ or physical proximity of family members to the person with bvFTD appeared to have an impact on the level of awareness and understanding of the changes taking place. As highlighted by Rena and Dave (p.147) and Jane Burton (p.142) being 'on the fringe of things' appeared to impact upon their ability to see what was occurring. It also seems possible that the way in which the person with bvFTD behaves with those in their wider family circle impacts upon awareness, For example, Anthony appeared to suggest that he behaved differently with family members who don't see him often (p.141-2). Furthermore, Melinda suggested that initially she had covered up the extent of the changes with their children:

Melinda *It was a real big change, because I was living with it and covering a lot of it up, they weren't kind of quite aware of how things were. [T1]*

The subtlety of the changes occurring early in the experience of bvFTD may also make it more difficult for others to become aware. It is conceivable that the changes in the expression of empathy in intimate relationships would be less apparent to those who are not in this type of relationship with the person with bvFTD and therefore not as close. For example, Kate discussed the change in their relationship and seemed to reflect on a shift from partners to parent/ child:

Kate *And you want the physical, the hold, reassurance when things don't go right and something's gone wrong or he's forgotten something or something's not happened right, just stands in the kitchen and says…*

Alistair *Just for reassurance.*

Kate *…"Oh I just need you." And he just needs…*

Alistair *Yes just the reassurance.*

Kate *Like you would when you pick up a child and you hug them it's kind of like that isn't it? Except he's too big to pick up ((laughs)) [T1]*

It also seems possible that others would be less aware of the subtlety of this change unless it was directly discussed. Indeed Kate seemed to suggest that it would not be the norm for discussions about intimacy to take place within the wider family circle (Table 7.7):

Table 7.7: The subtlety of changes
Kate *I think [Friend] expressed it one day she said, "Suddenly I hadn't got a lover and I got somebody I had to care for." […] and I absolutely totally understood that but it's not something you share. So you can't ever talk to anybody about [the change in intimacy]. I couldn't explain how I felt. […] everybody's quite happy to say, "How are you? Are you stressed?" or "You're looking well," or this but it's not a subject you can just bring up. I mean I realise that we're British and we don't talk about these things anyway, no sex*

please and all the rest of it [T1]

Awareness and understanding also appeared to be actively avoided by some. For example, Pamela described the apparent memory difficulties reported by her mother's husband:

> *Pamela her husband was saying, "Oh your mum's memory's terrible." And we didn't take any notice because in your 70s well that's age isn't it? Well this is what we thought; this is what we were hoping. [T1]*

At the end of this quote she appeared to imply that they didn't want to take his concerns seriously. This seems to suggest that another element influencing awareness of changes may be the readiness of others to hear and see the changes occurring. Similarly Dave, who is the father-in-law to Alistair Perrin, acknowledged that he didn't really want to know because of his fear that he might have dementia too. Other family members also seemed aware but appeared reluctant to learn more about the diagnosis. It is therefore conceivable that the experience of grief at the changes may also influence avoidance.

A further influencing element may be that of the prior relationship. As highlighted above, some families sought to engage a collaborative approach to responding to the diagnosis, whereas for others, differences in awareness and understanding appeared to lead to distance and disconnectedness. Those families that engaged in a collaborative approach seemed to have a relationship in which cohesiveness and reciprocity featured strongly, such as the Morris Family (c.f. Chapter 6). They had worked together to overcome adversity in their lives thus their response in this latest challenge appeared to continue this pattern of relating. Similarly, where communication between generations was the norm for some families (see Perrin and Morris families, chapter 6), this seemed to influence awareness. For example, wider family members may be exposed to the concerns that closer family members have about changes, as described by Rachel Perrin:

Rachel *I think you were telling me more than you were telling her, so she was seeing more but not hearing, whereas I was hearing more but not seeing. […] [T1]*

Even though Rachel was at University at the time, the patterns of relating within the Perrin family meant that she was in regular contact with Kate and therefore hearing about the difficulties that were being experienced.

However, cohesiveness and reciprocity did not feature as strongly between generations in those families who were distant and disconnected. For example, Mollie and Anthony described their relationships with family as not being central to their lives (c.f. Chapter.6). Although they appeared to have strong connections to their grandchildren, they identified at the second time point that relationships with Mollie's daughter had deteriorated (table 7.5). As indicated in that quote, they suggested that Diane had not accepted Anthony's diagnosis:

Mollie *She's seen all the pages…she's been on the website, Alzheimer's website, everything ((sighs)) I think it's just a dig because we weren't…she didn't get that attention at the time [T2]*

However it seemed that Anthony and Mollie believed that Diane held unrealistic expectations about the support that they could offer her. Similar difficulties concerning cohesiveness, reciprocity and expectations of support appeared evident between and within generations in the Lewin, Hugh, Horton and Stuart families.

The availability of knowledgeable and supportive professionals influenced families' awareness and understanding of bvFTD. In four of the families, the experience of help-seeking seemed to have been a frustrating and slow process in which a range of professionals were involved and where alternative explanations were offered before bvFTD was finally diagnosed. For example, in the Horton Family, Phil described a long journey in which they saw her general practitioner on numerous occasions before concerns were acknowledged. Referral to a number of different specialists

subsequently occurred before a diagnosis was finally offered some three years after help was initially sought (Table 7.8):

Table 7.8 A long route to diagnosis

Phil	*So when things started to get slowly worse I went back again and it was exactly the same again. "You need to go to Relate." […] She saw my wife on her own and then we went back together, for the consultation, […] And the actual GP said to me "Well what do you think is wrong with her?" And I said […] it would appear to me that she's got some form of Alzheimer's disease." So she […] did the mini mental test. When she was doing the test she said "Oh dear, we have got a problem." […] Then she sent us to see a specialist […] who had a brain scan done and said he could see nothing wrong with her brain scan and said "There's nothing wrong with her." So that set it back another year. And then because things deteriorated, just little things, we went back and saw the GP. She said "Well I'll send you to see somebody else." And then we saw Professor […] and he did some testing and they did a cognitive test […and then referred] for a third opinion and they'd come to the conclusion that she'd got some frontotemporal problem. And in 2008, after two years delay […] the Professor wrote a report where he said she'd got frontotemporal dementia […] So that was all done in about 2009, 10. [T1]*

Pamela and Jonathan Hugh also described a difficult experience with services, in which they felt that no-one was listening. Furthermore, they seemed to believe that the professionals they encountered didn't understand the nature of the difficulties that Elizabeth was experiencing:

Pamela *So we managed her over the Christmas period and I phoned her social worker and said what had happened and she basically said, "Well we can't send any carers in if she doesn't agree because it's against her human rights." […] And that social worker basically said, "I don't believe that there's anything wrong with your mother." [T1]*

Therefore some families experienced the professionals as out of step with their needs, lacking understanding and therefore unable to help them. In contrast, other families felt that the availability of professional support following diagnosis had enabled them to understand and develop effective responses to the needs of the person living with bvFTD (Table 7.9):

Table 7.9: Professional Support	
Melinda	*But I think it was the frustration of the build-up and then [the specialist nurse] was brilliant, because Bert will eat and eat and eat, because they forget he hasn't eaten. And she was brilliant because she was giving me ideas how to cope, […] And I think all the support you get that way, helps us to help Bert and that is why I think he's steadier now than he was six months ago, because we've all learnt to adjust to the way Bert is functioning, rather than us trying to impose, 'You should get up at this time, you should go to bed that time,' and we've kind of all learnt to adjust to the way you are. [T1]*

Therefore support from knowledgeable and responsive professionals may also be helpful in influencing the transition from awareness to understanding.

7.4 Managing everyday life

For all seven families, bvFTD had a wide ranging impact, affecting cognition, mood, social and relational functioning. Changes in functioning appeared to require adaptations so that wellbeing, relationships, activities of daily living and other aspects of family life could be sustained. Therefore the challenge of maintaining everyday living was present for all seven families who participated, particularly for the person with bvFTD and their closest family members. Narrative excerpts from all three time points contributed to this theme with three subthemes emerging from analysis:

- The impact of bvFTD on relationships
- The impact on independent activities of daily life
- The impact on self-care, health and well-being

Some of the main features of bvFTD are discussed in each of these subthemes. While other features of bvFTD and their effects are evident in the data, in light of the word limit, it is the main features that are considered here.

The impact on relationships

Changes impacting upon relationships with wider family members and other social situations are discussed here. Although there is inevitably some overlap with changes presented later in this chapter, under the theme **We're not the same anymore.** As in that section, I describe those changes that affected intimate and close relationships between couples or adult children who are co-resident or closely involved with the person with bvFTD.

Intergenerational relationships are important in everyday life and appear to feature strongly in the lives of the participating families in this study. Similarly relationships with their wider social circle also appeared important to some. Furthermore, social contact in everyday settings is a regular feature of life, for example, in employment, shopping and similar activities.

As described in Chapter 2, bvFTD impacts upon social cognition including; empathy, social behaviour, impulsivity, disinhibition and social interest. All of these are likely to have an impact on relationships within families and in other social spheres. Similarly, the impact of bvFTD on wider executive functioning involving the monitoring of own behaviour and flexibility of thinking may also affect relationships.

Table 7.10 describes the apparent changes in social cognition experienced by Bert and the consequences of this change for his behaviour and its impact on others.

Table 7.10 Impact on social cognition: Bert and Melinda

1 *2* *3* *4* *5* *6* *7* *8*	**Melinda**: He gets very angry; if you say you're going to do something and they don't, he gets very angry and then when he's had the outburst and then you kind of ... **Bert**: But sometimes you have to be mindful about, it's all right sort of going on one about something when it doesn't happen, but you've also got to try and think of the bigger picture with your relationship with that person, whether it's your son or your daughter.	Difficulty monitoring own behaviour Cognitive empathy Difficulty with

9	**Melinda**: We try and after each outburst, if there's an outburst with	empathy (in the moment)
10	him, I will ring whoever it is and talk them through it, because it's	
11	very hard when you've had this very loving dad, who has always	Impulsivity
12	been very calm and will talk things through, to one that will just go	
13	like that ((snaps fingers)) […]	
14	**Bert**: Yeah, but if I were to say something to them, it would be less	
15	of a problem than what it would be somebody outside. I mean	
16	when you've ...	
17	**Melinda**: He's lost his temper in shops.	
18	**Bert**: ... parked up ready to go in and then you've got some other	
19	clever bloke zips in behind you ...	
20	**Melinda**: He loses it.	Emotion regulation
21	**Bert**: ... I've got out and lost it a few times.	
22	**Melinda**: […] Because normally, before we go out to do anything,	Impulsivity
23	we go over what we're going to do, what we've got to look for and	Affective empathy in the moment
24	I'd forgotten to tell him about unreeling the cable and he lost it in	
25	Wilkinson's. And this gentleman came to try and help him and he	
26	was really abusive to him and told him to f*** off and all sorts, […]	perspective taking, empathy impulsivity and irritability
27	**Bert**: The thing is, if you say something or react to something with	
28	your family, they're less likely to become confrontational, because	
29	they'll be going along the line, 'Well, what's happened there?	
30	What's caused that? What have I done to cause it?'	
31	**Melinda**: They just take themselves off now.	
32	**Bert**: Whereas, when you're in a situation outside your family, that	Cognitive empathy
33	in itself will cause that person to be confrontational with you and	
34	it's very easy then to get that out of hand.	
35	**Jenny**: Are you aware, Bert, that that's happening? Do you realise	
36	what's going on?	
37	**Melinda**: Not until after, the shock of somebody's face tells you,	Impairment of empathy 'in the moment'
38	doesn't it?	
39	**Bert**: Mm.	
40	**Melinda**: He doesn't realise when he's doing it, because [the	Unable to recognise distress in others,
41	dementia is] a tyrant, this isn't the Bert we know. It's the look of	
42	horror, I think, ((laughs)) on somebody's face.	
43	**Bert**: Yeah, because if I've felt outside of my family how that other	
44	person reacted, because I thought they were in the wrong, but they	difficulty with perspective taking
45	thought, by their stance, that they're in the right, then it could be ...	
46	I would probably take it to the next level.	
47	**Melinda**: That's one concern he has, that's why he wouldn't dream	Difficulty monitoring own behaviour. Not able to 'read' the reactions of others in the moment
48	of going off on his own shopping. If we go out, [where], there's	
49	more shops, he would never go in a shop, he would stand on the	
50	outside, because he says, 'I haven't got to face any confrontation.'	
51	Because I think slowly you've realised ...	
52	**Bert**: That's why I don't like answering the phone, because at the	
53	end of the day, you can say nine times out of ten, you're going to	
54	have to make a decision or say something that could cause a	Evidence of cognitive empathy
55	problem. I just don't do it. [T1]	

In the above quote, at different points Bert seemed to be able to reflect on and recognise that his frustration and anger in specific situations had an impact on his adult children. He also seemed to recognise that this affected others who he came into contact with when out shopping or in other social situations. He appeared to recognise that he needed to modify his behaviour because of the impact it may have (lines 4-8 and 52-5).

However, he also appeared 'in the moment' to be impulsive in his responses and unable to take the perspective of others, read their nonverbal cues and modify his behaviour accordingly. Furthermore his responses seemed to suggest that during these incidents he experienced difficulty with affective empathy (lines 1-3, 21-6, 40-6). These actions seemed particularly likely at times of stress such as when routines were disrupted. Melinda described how difficult their adult children had found this when they had been used to someone, who she suggested, had previously been considerate and loving (line 9-13). The above quote alludes to strategies which have included attempting to understand Bert's perspective and walking away. It is nevertheless evident that such behaviour can have significant consequences for relationships with wider family, particularly if that behaviour is not understood. Similarly, the potential impact of this behaviour in social situations is considerable. As Bert described, he felt he would be less likely to be able to control his behaviour when with someone he didn't know. The Morris family appeared to work with Bert to manage the triggers for such behaviour when outside, as evidenced in lines 47-55.

Consequently, reductions in features of social cognition including empathy, interpersonal relating, perspective taking and executive functions including monitoring of own behaviour and impulsivity impacted upon relationships with wider family members in this research. Some people living with bvFTD retained cognitive empathy to the degree that they could reflect on their behaviour and its impact in relation to specific incidents or experiences. However, their capacity for affective empathy particularly when 'in the moment' seemed to be significantly affected. Furthermore, such difficulties had the potential to impact upon everyday social interactions, thus providing

many challenges for the person and their family in their everyday lives together.

While difficulties in relationships were a consequence of the experience of bvFTD, it seemed that it was also possible to maintain relationships with some wider family members. Indeed for the five people with bvFTD who participated, relationships with their grandchildren continued to be positive and a source of joy for them:

> *Ray* *The pleasurable things […] Grandchildren of course.*
>
> *Jenny* *Tell me a bit about Leo and Phillipa?*
>
> *Ray* *As you see them grow up it keeps you young I suppose. It keeps you on your toes and […] Leo likes to see me and he comes in and plays with my chair and he can be a bit of a handful but in a nice way. I mean he's always playing now with my controls on my chair and he gets it, like he knows where all the contraptions are. […] So yeah they keep me going […] So very good I think. It's good to have your grandchildren around you, […] [T1].*

Ray seemed to value the contact with his grandchildren and felt that they had a meaningful impact on his life. It seemed nevertheless that there were limitations to the nature of their activities with them and in their relationships over time. For example, Kate appeared to suggest that Alistair was no longer able to be responsible for the grandchildren at time point two. Furthermore, some families seemed to notice differences in the ability to relate to older and younger grandchildren as the person's difficulties became more pronounced. For example, Mollie and Anthony suggested that Anthony enjoyed the activities their youngest grandchild Isla wished to engage in which seemed less demanding:

> *Mollie* *He loves it. […]And if you see them together it's like watching two children. "Come on Granddad. Come on Granddad. Let's go. Let's go in the garden Granddad." And then the next thing you've got the pair of them are at the front door ringing the*

doorbell to come in. And that's when they go off, toddle back round and they come...

Anthony *Isla's out the back door and she runs round and...*

Mollie *Yeah and you lift her up to ring the bell. [T3]*

However they had gone on to explain that he had struggled with games of scrabble with their older grandchild Chloe. It is conceivable that the activities of older children may be more complex and therefore more demanding, making it difficult for the person with bvFTD to manage. Nevertheless, some of the families also suggested that their older grandchildren were responsive to the needs of the person with bvFTD and accepted the way things were with them:

Kate *Freya said to me, "Nanny when Grampy gets difficult you know you can always come to me," she said and I said, "Yeah I know thank you darling," ((laughs)). She's a good little soul.*

Alistair *Yes she is. And I'll say to her, "I'm sorry I don't recall that." "That's all right Grampy it'll come back". [T3]*

The above highlights some of the specific challenges for relationships and social interaction brought about by bvFTD. It is clear that bvFTD has a significant effect and has the potential to impact negatively on relationships, both with non-resident family members and within the wider social circle. For example, Melinda and Bert referred to the loss of friendships:

Melinda *One friend that we had, that we thought was a friend, we'd just found out he'd got dementia, we told them and that was it, we've never seen them.[T1]*

Mollie and Anthony also highlighted the conflict with her daughter (Table 7.5). However this does not preclude the ongoing potential for positive relationships as described above.

The impact on independent activities of daily life

As described in Chapter 2, bvFTD has an impact on specific aspects of executive functioning, often referred to as adult higher brain functions

including planning, initiating, monitoring and stopping behaviour. Furthermore, bvFTD also impacts upon processing and sense making, judgement and decision making. These changes seem likely to have a significant impact on the person's ability to be in control of their lives. Participants' accounts highlighted the impact of these cognitive changes on the range of functions that are necessary for everyday life.

Frequently, participants referred to changes in their ability to manage complex tasks occurring early in their experience of bvFTD. These included activities associated with employment, driving, household DIY or the ability to manage the activities of others. Furthermore, these difficulties also affected less complex activities such as using a shower or a microwave. Tables 7.11 and 7.12 give two examples of the impact upon wider executive functions including sense making and processing, judgement and risk taking:

Table 7.11: The impact on everyday life		
1	**Sue**: I'll tell you what he did, because I find it hard to do some	
2	aspects of my cleaning and I said "This shower needs	
3	cleaning.", because it's just, doing the tiles, I can't stretch up.	
4	So I said "Would you do it for me?" and I was doing some	Sequencing
5	ironing and I left him. I said "I'm not going to interfere, you don't	Difficulties with planning implementing and monitoring, sense making and processing
6	like me interfering." And I had all of the things for what it's	
7	needed and other things. And he was squirting the bathroom	
8	cleaner on the tiles with this grouting brush, but no water. And	
9	he says to me "This cleaner has fumes. And he said "Now I've	
10	just squirted it and then wiped it with another cloth."	
11	**Terry**: I'm not a domestic.	
12	**Sue**: No, but since we've been here you have done it numerous	
13	times. But he just completely forgot how he'd got to do it. […]	
14	And so of course I had to do it myself. […] So he shouts at me.	
15	"Oh, I'm useless." and all this. I said "Why didn't you ask me if	
16	you weren't sure how to do it?" I said "I just didn't want to keep	
17	coming in, you tell me off. 'Can't I do anything on my own?'	Motivation
18	and all this." This is what it's doing to us. I'm trying to motivate	
19	him to do something, but he makes such a mess of doing	
20	something and I think "I might as well do it myself." [T2]	

In the quote above, Sue described the difficulty that Terry had in undertaking an everyday task (lines 1-13). It seemed from her description of the situation that Terry experienced difficulties with executive function, including planning, sequencing and monitoring the actions he needed to take to achieve the task (lines 6-13). Furthermore Sue suggested that he also experienced difficulties with motivation. Similarly the excerpt from Kate in table 7.12 (lines 21-55) appears to highlight difficulties with concentration and attention, as well as

judgement and decision making (lines 42-50). Kate described Alistair's difficulties with driving, a task he was previously highly competent at:

Table 7.12: The impact on everyday life		
21	**Kate:** […] And he's certainly not managing as well driving. But	
22	fortunately, […] I got to [Outpatients appointment] before he did	
23	and I said to the receptionist "I've got a problem, because I need	
24	to let them..." so she went and spoke to the doctor and I could	
25	write down my concern on a piece of paper. And so she could	
26	bring it up as part of the, without knowing that I'd got, because he	
27	gets ever so cross when you mention driving. And she brought it	
28	up. But in the meantime I'd spoken to the guy, because I'd redone	
29	my minibus license and the guy that tests me also is the assessor	
30	for the driving. Because he said to me "Where's Alistair?"	
31	Because we always do our test together. […] And I explained. And	
32	I said "There's no way he could drive a minibus now." and he said	
33	"No, no, no, definitely not." I said "I'm not even sure about his	
34	driving.", […] Alistair [will] say "I don't need [an assessment]!", so I	
35	said "Okay then, that's fine. You don't need it. You know [the	
36	driving assessor] because he's tested you. You trust [his] word.	
37	Let's go by what [he] says. If [he] tests you this year and he says	
38	you're fine, I won't go on at you anymore." So he said "Yeah." And	
39	I said "But if [the driving assessor] says you're not fine, you have	
40	to abide by [his] decision. Is that a deal?" So he said "Yes." […]	
41	**Jenny**: What's concerned you about his driving?	
42	**Kate**: The fact he gets distracted. He doesn't seem to be able to	Attention and concentration
43	see when something's dangerous. His spatial awareness isn't very	
44	good, so we often are very close to the car in front which frightens	Judgement and decision making
45	the life out of me. And the car in front is braking and he's still	
46	accelerating. And I'm trying to get out (laughter). He says he's not	
47	and it's my imagination and I'm being neurotic. However I wasn't	Attention and concentration
48	neurotic when we nearly ended up in the ditch in France because	
49	he saw a cow in a field and he went "Ooh, look at that!" So that	
50	was a bit hairy. I haven't let the children get in the car with him He	
51	hasn't worked out yet that I haven't let the children get in the car	
52	with him, but it does worry me that he says that it's not. And then	
53	it's, again, not helped by Mum and Dad because when they get in	
54	the car with him Mum says "There's nothing wrong with his	
55	driving."(sighs). [T2]	

As well as the relational difficulties described earlier in this chapter, the potential consequence of these difficulties is a shift to a position in which the family increasingly had to take responsibility for the management and achievement of activities of daily living (lines 12-13). Furthermore, lines 21-39 highlight that taking responsibility also involved those closest to the person

having to make decisions independently of the person with bvFTD concerning these activities and safety. Sometimes those decisions created conflict as the person was unaware that their behaviour was inappropriate or unsafe (lines 32-38 and 44-47). Consequently family members may feel the need to resort to underhanded means to address issues of concern such as those expressed by Kate (lines 21-40).

As the difficulties progressed, greater input appeared necessary. Pamela and Jonathan describe a typical week of involvement in Elizabeth's life (table 7.13):

Table 7.13: Increasing needs

Jenny: So thinking about a typical week what does that involve for you in terms of supporting your mum?
Pamela: Well for instance this week what have we done this week? Jonathan's taken a phone call from the […] electrical shop. I've seen [the nurse] today.
Jonathan: There will be a call from the care provider about something, there's always a call about something.
Pamela: Today I've spoken to Wiltshire Farms about her delivery of food. We have all the post redirected here so that we deal with that. I've had an email today from her accountant…
Jonathan: Who's also the power of attorney.
Pamela: Who wants her P60 so that he can complete her tax return. On Friday I shall be at her house sorting out her key safe so that her key is available for [the food delivery]
Jonathan: We'll take wine won't we probably once every ten days and hide that in the garage for the carers to access. […] Usually something goes wrong in the house and needs to be…or the garden and needs to be sorted out.
Pamela: But today she's phoned up because the iron's broken.
Jonathan: The iron's broken.
Pamela: So she needs a new iron. But the thing is I never, ever take what she says as being true so I'll have to actually email the carers to see whether that is accurate information.[T1]

Furthermore, some family members appeared to feel that they were unable to leave the person alone due to the level of difficulty they experienced with everyday tasks:

Phil *I couldn't cope with being away from the situation and leaving her on her own, because I knew she didn't know how to look after herself and I didn't know that she'd be safe in the house without some support or somebody with her. I'd go to*

work and it would be at the back of my mind all the time, that there'd be a problem. And the care worker would come in and then I'd go to work and then the care worker would phone me and say "This has happened." or "That's happened." or "The other's happened." So I just realised I couldn't commit to a demanding job […] Because you can't do the two, there's no way. [T1]

In the examples given above, bvFTD progressed to the point that it restricted many activities, impacting upon employment, personal finances and lifestyle for the person with bvFTD and their close family including partners.

The impact on self-care, health and well-being

Difficulties occurring as a consequence of bvFTD such as executive function and social cognition also impacted upon self-care. Some families described difficulties involving motivation to shower and change their clothes, For example, Mollie indicated that she had to prompt Anthony to take a shower:

Mollie *[Anthony] wasn't sort of washing and showering. He'd argue with me, "No, I had one yesterday" and I'd say to him, "No, you haven't had a shower love for about three days". [T1]*

Mollie and Anthony also described difficulty with dressing, particularly when buttoning up shirts or when putting on underwear. These difficulties increased over time, as suggested in Table 7.5, as by time point two, Mollie seemed to be involved in high levels of prompting and supervision. Mollie also suggested that Anthony had difficulties with motor co-ordination and described having to monitor him when they were on the boat together as he had become unsteady. Melinda and Bert also described similar difficulties resulting in falls,

Melinda *Yeah. You've had a couple more since then as well. When your leg gave way and you didn't know what that was. That was frightening because that was really early.*

Bert *That was in the early hours of the morning and if you'd never got up. Had a drink and just for no reason just collapsed. My right leg just went. And I went down like a ton of bricks. [T2]*

These difficulties appeared to result in close family members needing to take responsibility for prompting and supervision on a daily basis.

Two of the families also noticed changes in eating habits, resulting in weight gain:

> *Kate* *The food is certainly a filter that's gone.*
>
> *Alistair* *Yes […] if it's in front of me I'll keep eating. […] Yeah that's a process I've got to do.*
>
> *Kate* *Not to the quantity though!*
>
> *Alistair* *True! But I can't it's there. […] If they kept putting the food in front of me I'd keep eating. [T3]*

As the above quote suggests, Alistair felt compelled to eat what was in front of him. He did not have the capacity to regulate his food intake, but was also resistant to attempts to change his diet. Rena and Kate suggested that he had become fixated on sweet foods and was also quite rigid in what he would eat. While they appeared to feel that this was an exaggeration of previous traits, it nevertheless seemed to be a source of concern due to Alistair's weight gain and his health. Similarly Pamela and Jonathan described difficulties in monitoring and restricting Elizabeth's alcohol intake. Like Alistair, she appeared not to be able to instigate self-control consequently they described having to do this for her.

Four of the families described disturbed sleep patterns. For example, Alex described that Ray woke frequently during the night:

> *Alex* *He's getting me out of bed two or three times a night and when I get down here, hobble down the stairs and I say to him, you know, "It's not easy for me to go up and down stairs, up and down stairs in the middle of the night". [T3]*

There were different reasons for disturbed sleep patterns among the people living with bvFTD including motivation, sleeping during the day and anxiety. However it seemed to have had a significant impact upon family members as Alex described in the quote above.

A final feature of the impact of bvFTD seemed to be its effect on mood. Two of the families described changes such as low mood and increased anxiety

Neither of the persons' with bvFTD appeared to recognise this in themselves as described below by Anthony:

> *Anthony* *I didn't feel that I was ever depressed. I feel lucky to be alive and notice each day as it comes. Every day is a bonus. So I couldn't understand how I could possibly be depressed. But I could get tearful ever so easily. And I would withdraw as well, into myself a lot more and have quite long quiet spells. [T3]*

Indeed it was ultimately Mollie who raised this with their GP following which Anthony was prescribed anti-depressants. It seems therefore that as with activities of daily living, difficulties with monitoring and managing self-care and health created increased responsibility for those closest to the person with bvFTD. The range of responsibilities appeared to rise as bvFTD progressed.

7.5 Influencing Elements

A range of influencing elements seems to be relevant to this theme;

- Prior relationship
- Awareness and understanding within the family
- Awareness – Unawareness, person with bvFTD
- Availability of knowledgeable and supportive professionals
- Past experiences of similar difficulties
- Peer support

Some of these have already been addressed in this chapter, thus they will be summarised here with additional comments where necessary. Each of these is now addressed in turn.

Family relationships prior to bvFTD have been considered in Chapter 6 and their influence on the challenge of awareness and understanding has also been discussed (p.152-3). The issues described there are equally relevant to this challenge, as past relationships appeared to influence the way in which behaviour was interpreted and understood; the extent to which families were able to collaborate to develop their understanding and the way in which they supported each other to cope. These are discussed more fully in the next chapter (Chapter 8) where coping processes are described.

Similarly, awareness and understanding within the family is an important influencer and has already been considered in this chapter under the challenge of awareness and understanding of the changes (p.139-50). As described in this section having a shared understanding of the changes and therefore the reasons for a person's behaviour appeared to influence the development of coping processes. In the absence of such understanding, it appears that there is a risk that the person will be criticised for their behaviour, as seems to occur with Sue (Table 7.4). Furthermore it may cause conflict in relationships between generations as described by Mollie and Anthony (Table 7.5). Similarly, the availability of knowledgeable and supportive professionals has already been addressed in this chapter (p.154-5). As can be seen in that discussion, professional support to understand the impact of bvFTD and consider how best to cope seems to be an important element influencing families ability to move from awareness to understanding and to consider how best to manage the challenges to everyday living.

Members of three of the families had past experiences of difficulties which appeared to enhance their understanding of the experience of bvFTD. For example, Kate described her own experience of dyslexia and her work supporting children with special educational needs and particularly with children who experienced autism. Alistair and Kate's daughter, Rachel, also has Asperger's and dyslexia, consequently the family had previously worked together to develop strategies to support Rachel. As can be seen in the quote below, they combined these experiences with knowledge gained from others to develop coping mechanisms (Table 7.14):

Table 7.14: Using past experiences to understand bvFTD

Alistair	*You had a friend that had a brain injury and information that he was giving you from that sort of put two and two together and... And with you working with – I'm trying to find the words now. Children that […] need that extra little bit of help at school and stuff like that so... putting that in.*
Kate	*Because of the SENCo work I do […] what I did was took everything I knew from there and converted it to making it work. What would I have done for a child that couldn't process? Well I*

would have put in a visual timetable, […]

Melinda and Bert also referred to their son's experience of dyslexia and the insight this appeared to have given them. Furthermore Jane Burton also referred to her experience of working with children who have communication challenges and using this experience to support communication with her father.

A final influencing element seemed to be that of peer support. A few of the families including the person with bvFTD described the value of peer support in helping them to understand their experience and develop strategies. For example, Anthony and Mollie found the Alzheimer's cafés to be an important source of support for both of them (Table 7.15):

Table 7.15: The value of peer support

Mollie	*I think we get out a lot more than we did, don't we. And we're out mixing with people. We both get out. You go out, you're talking with people who you know with dementia and other carers and stuff.*
Anthony	*We go to the Al's Cafs and meet other people in a similar position to yourself […]. And then you pick up little ideas and tips off other people and find out how other people cope with it. And they come out with things that you never even thought of and you're thinking 'Oh, well why didn't I think of that?' But you're so stressed out all the time so you can't think straight. So you support them and they support you. It's good. [T3]*

As their narrative seemed to suggest, the opportunity to hear others' experiences and learn from them was an important influence on finding ways of managing the challenges associated with everyday life.

7.6 Being me in the context of bvFTD

'Being me in the context of bvFTD' represents the challenge for the person with dementia to maintain their sense of self, identity, agency and safety in the face of the challenges brought about bvFTD. All five of the people living with bvFTD who participated in this research contributed to this theme.

Narrative excerpts from all three time points contributed to this theme, with four subthemes emerging from analysis;

1. You’re not the same anymore
2. I know I’m changing --- I’ve not changed at all
3. I don’t feel in control
4. I need to feel safe and secure

You’re not the same anymore

As demonstrated earlier in the section on managing everyday life, it seems that bvFTD has a wide-ranging and significant impact. Family members commented openly on the changes they had noticed. For example, Kate reflected on the change in Alistair since he began to experience bvFTD (table 7.16):

Table 7.16: You’re not the same anymore

Kate	*He's forgetting things. Can't get his brain into gear, can't process stuff. He must have said ohhh nine or ten times in the last four days “Brain into gear. Must get it into gear.” He's trying to use his initiative. […] Because he thinks he's helping, he starts something and then gets distracted and doesn't finish. [...] And so the inability to think of something and work through the consequences if he just does this little bit and doesn't do the rest has gone pretty much. That's a noticeable decline. Yeah, I think that's one of the things that's hardest. […] But he's also a very lovely man. And that's the thing that's hard, when he gets unpleasant, because that's out of character. It doesn't happen often, but he gets really quite shirty with the way he says something, as though you're a complete idiot and you've got no idea. And that's just not characteristic and it's not the Alistair that I know. Well, it is the Alistair I know now. But it wasn't the Alistair I married. [T2]*

Alistair’s family appeared to have viewed him as a thoughtful, caring and competent man (c.f. chapter 6). Kate’s quote highlights the significant changes she has noticed in those valued characteristics since Alistair began to experience bvFTD. Similar narratives are evident in other families, most

particularly from the person who lives with the person with bvFTD or is most closely involved with them.

I know I'm changing --- I've not changed

While family members acknowledged significant changes, the five participants living with bvFTD appeared to have varying degrees of awareness about the nature of the changes that they experienced as a consequence of dementia. Additionally they also had varying levels of awareness of the impact this had on them and their relationships with others.

Alistair and Anthony and to a lesser extent Bert and Terry, recognised that they experienced changes in cognition and in the way that they responded and related to others. They also appeared to have some recognition of the influence of the changes on relationships with their family. Anthony described noticing cognitive changes particularly in relation to complex tasks even before he received his diagnosis (c.f. table 7.2). His awareness of these difficulties continued throughout his involvement in the research. Additionally, he recognised that his cognitive abilities were changing to the extent that less complex activities were challenging by the final time point:

Mollie *Yeah. You still go through your post, don't you, even if he doesn't remember what he's read, he still goes through his post and pops [it] down the desk round the corner and that's it. But he still looks at his post.*

Anthony *It's when you put it down's the problem. It vanishes then.*

Mollie *But you'd need about an hour to sit and digest whatever it is you're reading, don't you. At least. You keep going over it.*

Anthony *Read it over several times before I can digest it. [T3]*

These changes seemed to have a profound impact on his life, including having to give up work earlier than intended and gradually having to relinquish many valued activities to his wife Mollie. Indeed he seemed to acknowledge that their roles had shifted and described Mollie as the captain now, with him being the crew. Similarly Alistair, Bert and Anthony also appeared to have awareness of the changes they experienced in the way they relate to others. For example, Bert appeared to recognise the impact of

his behaviour towards his children and grandchildren at both the first and second time points in the research (Table 7.17):

Table 7.17: Awareness of the impact of behaviour on family

Melinda	*He gets very angry; if you say you're going to do something and they don't, he gets very angry and then when he's had the outburst and then you kind of ...*
Bert	*But sometimes you have to be mindful about, it's all right sort of going on one about something when it doesn't happen, but you've also got to try and think of the bigger picture with your relationship with that person, whether it's your son or your daughter. [T1]*

Melinda	*What about when you shout at them?*
Bert	*Who?*
Melinda	*The kids. When you kind of, he can be quite abusive.*
Bert	*Yeah, I get quite... But I tried to, I suppose sometimes things that they do get on my nerves a bit, but then I always think about, I don't want them to think of me as a grumpy old granddad which you see on the telly. So, that in the back of my mind there makes me think. [T2]*

In the above quotes, Bert recognised that he struggled to control his frustration but he also seemed to recognise that it's important to try and do so because of the impact that it will have on his family and the way that they view him.

Some of the participants acknowledged that their level of awareness was shifting and that they didn't always recognise the changes that were occurring. Terry suggested that he wasn't aware of when the changes first started and indicated I should ask others:

Jenny	*When did you start to notice things were not quite right for you? […]*
Terry	*Don't know. No I can't give you a truthful answer to that you know to be honest. Other people will have to do that. [T1]*

Anthony also described a change in his behaviour towards others that he wasn't initially aware of:

> *Anthony* *I could be quite snappy and abrupt with people. And I didn't really notice it in myself, that I was doing so. It had just, I suppose, become the norm. But other people noticed it obviously and I didn't. [T3]*

Both appeared to accept that that their awareness was not necessarily in keeping with the level of changes that others noticed. Furthermore, it seemed that while it may be difficult to hear, four out the five participants with bvFTD accepted that others in their family might have a greater awareness of the ways in which they were changing than they had.

However, even though some of the participants with bvFTD described changes, they did not always appear to be able to fully engage emotionally with the consequences of these changes. For example, both Alistair and Anthony were particularly articulate in describing the impact of bvFTD on their relationships. However, when describing these changes, neither Alistair nor Anthony seemed to express a significant emotional response. Indeed, despite the distress that Kate experienced when Alistair described the change in their relationship, he did not appear to be able to consider the emotional impact he experienced as a consequence of this change. Nor did he appear able to respond empathically to Kate's distress, something I noticed and recorded following the interview. I recorded it because I became aware that this lack of empathy was only evident in his non-verbal behaviour towards Kate (Table 7.18):

Table 7.18: Being able to engage emotionally with changes

JLF [T1]	*He looked at her a lot during our discussion and was attentive to her. He didn't however show any affection towards her when she was tearful, or indeed appear to recognise the impact it had on her and I am left wondering if this is normal for them? However they said that they cuddle and hold hands now. […] it was possible to discuss with them what bvFTD had meant for their relationship and Kate talked openly about the loss of intimacy and the change in their closeness. Alistair acknowledged it but didn't seem emotionally engaged with it. (field notes)*

While some acknowledged and indeed appeared to accept their diagnosis, Ray had much less awareness of his diagnosis and its impact. He often appeared to deny that he had dementia and even when acknowledging that he had received this diagnosis, was unaware of the impact it was having on him:

> *Ray* *So as long as you've got your brain to a certain degree into a gear which you know what you're doing you'll exist but as soon as you start losing interest you start going downhill. And touch wood that isn't to a stage yet but all I will say is I've seen a lot worse people with in homes than me i.e. dementia which I suppose I've got but it's not showing up on me yet [T1]*

In contrast his family described considerable changes in him and in his behaviour:

> *Sarah* *You just think well you're, everything that he was, he now is the contrast of, in my opinion. [T1]*

However, Ray did not appear aware that these changes had taken place. It seemed as though he compared himself favourably with people that had dementia who lived in the care home he went to for respite and had concluded that he didn't have dementia in the way they did.

As suggested above, the participants living with bvFTD appeared to have varying levels of awareness of the impact of dementia. Even where they had awareness, some appeared to recognise that they were not always aware of changes to the same extent as those around them. Furthermore, some of the participants did not appear able to engage fully with the emotional consequences of these changes for them or for their family. It is nevertheless clear that the changes brought about by bvFTD had the potential to have a significant impact on self-concept and identity, through the loss of valued roles, the change in relationships and the way that significant others perceived them. As well as the potential impact on self-concept, it appeared that bvFTD caused difficulties with feeling in control of one's life and being able to maintain one's own safety and security.

I don’t feel in control

Four of the five participants living with bvFTD contributed to this subtheme (Ray, Alistair, Terry and Bert). Being unable to make sense of and control their world seemed to be a feature of their experience of living with bvFTD. Some of the participants were able to directly comment on this difficulty. For example, Terry described how challenging it was for him at times to process, make sense of and achieve tasks that previously would have been possible for him:

> *Terry* *It's like a maze. Sometimes you can go round the maze, get through and come back out without any problem. But sometimes you can go in and you can't get out. And it's like that. [T2]*

He compared the difficulty he experienced with that of negotiating a maze, recognising that his ability to make sense of his world fluctuates. It appeared that when he couldn’t manage this, it could result in him feeling out of control. Alistair also reflected on the difficulty he had in this regard and seemed particularly to feel out of control when in unfamiliar environments and/ or with strange people (Table 7.19):

Table 7.19: Feeling out of control in unfamiliar environments

Alistair	*The first time I go to a place I'm looking, my mind’s on overtime, where’s the toilets, where’s this, where’s the doors, if I go over there how do I…you know. And if it’s a large room where there's lots of people in there, you know, will I recognise them things and pointed, things like that, back to where I'm sat or whatever, so that all that is going through my mind and then it’s what happens if I can't? You know it comes into my mind and then the panic comes in and I get stressy and not worked…*
Kate	*Upset.*
Alistair	*Not upset straightaway, panicking that I won't be able to work it out. [T3]*

Alistair clearly described the difficulty he experienced in trying to make sense of this new environment and also how being out of control could lead to feelings of panic. Terry's and Alistair's narratives suggested that struggling to make sense of and control their world was an ongoing feature of their experience over time. Indeed Terry described the sense of helplessness he felt (Table 7.20):

Table 7.20 being unable to control the changes

Terry	*But there's all these factors that's come on, which makes me a zombie.*
Jenny	*That's how it feels for you?*
Terry	*Yes and I don't want to be like that, but it's out of my remit, isn't it?*
Jenny	*It feels out of your control?*
Terry	*It is, yeah.*
Jenny	*And what does that mean to you, what does being a zombie mean?*
Terry	*It's like something that's chipping away, which I can't get back. I don't know whether it's a design or what. Because I ain't like that, I mean basically. But it's sad in a way, isn't it, very sad, but as I say, I can't do nothing about it. If I could read up about something and do something, I'd do it, whenever. But as I said, it's gone, the brain's all gone and what can you do? [T3]*

He likened his experience to being a zombie, emphasising the sadness he felt at being unable to control or influence the way in which bvFTD affected him. His quote highlighted that while he wished he could change the course he recognised that he could not. Similarly, Bert and Alistair appeared to share the concern that they were unable to influence the future and how their condition might change over time.

I need to feel safe and secure

In addition to the difficulties associated with feeling out of control, two of the participants, Alistair and Bert, expressed a sense of feeling unsafe and insecure which they both combat through holding to routines. Their sense of safety was upset when their routine was disrupted. A fundamental aspect of Bert's lived experience appeared to be his need for routine and for things to

happen in a predictable manner. For example, Bert and Melinda described how difficult Bert had found her emergency admission to hospital, which resulted in a disruption to his routine and therefore an escalation in his irritability:

Melinda *But […] I think it was a shock to them as well how their dad was. They couldn't quite understand how he was ticking, how... verbally abusive he'd become because he couldn't understand what was going on. […] but he was feeling in turmoil I'd say wasn't you?*

Bert *Yeah.*

Melinda *You know you were just kind of…*

Bert *Well you feel insecure don't you?*

Jenny *Right.*

Melinda *Yeah and your head felt like it was going to explode you said at one point. [T2]*

Furthermore, the above quote highlights that for Bert, the absence of Melinda was also central to feelings of insecurity. Bert and Melinda subsequently described Bert's fear that Melinda wouldn't stay with him:

Jenny *So that was a worry for you, that Melinda wouldn't stay with you.*

Bert *Well, yeah, because that was one of the reasons why in my mind we went to the doctors in the first place with what was happening. Because I knew, I felt there was something wrong, didn't know what it was, but obviously I felt that I was putting a lot of pressure on her. Like everything else you can take so much pressure, then you just give up then, don't you. Or you become ill yourself or whatever. Or it affects you in different ways. [T2]*

Similarly, Kate commented on how important it was for Alistair to know where she was in order for him to feel safe and Alistair confirmed this:

Jenny *So it sounds as though Kate being around is really important.*

Alistair *Yes it is important. […] Yes being there, just being in the vicinity yes. […]*

Kate *Because I made him feel safe.*

Alistair *Safe yes.*

Kate *We were talking about it when we were [on holiday] and I said, "Why do you need me so much?" […] And so we've talked about it and he said, that you make me feel safe. [T3]*

It seemed that panic and distress were significant consequences of feeling out of control and insecure. This sense of panic was evident in all four of the participants' narratives. For example, Kate and Alistair suggested that he would get panicky when he didn't feel safe:

Kate *Because what happens is then the panic kicks in and then he can't see anything except a sea of faces. So even if I'm standing right in front of him going, "I'm here, I'm here," it…*

Alistair *Nothing's recognisable it's all just a blur.*

Kate *The panic has taken away the last vestiges of… [T3]*

Kate suggested that Alistair was unable to control this sense of panic once it had started and that the panic seemed to take away Alistair's ability to reason and respond to her. Sarah and Alex Lewin suggested that Ray experienced a sense of panic and it seemed that he also was unable to control this once it had started. Furthermore, Terry also appeared to experience a sense of frustration and anxiety when his ability to maintain a sense of safety and security was challenged, which may have contributed to his angry and defensive responses.

7.7 Influencing Elements

A range of elements would appear to influence this theme. These include:

- In step or out of step in our awareness of changes
- Family coping processes
- I trust my family's ways of supporting me
- Sense of self
- The impact of bvFTD on social and cognitive functioning

- An important person in our lives --- he was just there really
- Understanding their emotional world

Some of the people living with bvFTD and family members appeared to have more awareness of the changes that had occurred than others. Where awareness of the changes was present and there was some congruence between the person with bvFTD and their family, it appears that this may offer the potential for collaboration to occur in understanding the nature of the changes and what the person might need. Additionally it may also support opportunities to find ways of managing challenges, which support the maintenance of selfhood. For example, Anthony and Mollie explained how they had managed the difficulty Anthony had with operating kitchen appliances, thus maintaining his independence (Table 7.21):

Table 7.21: In step and able to collaborate

Anthony	*Once ((Mollie)) showed us what to do I thought: 'Oh yeah, of course, press that; silly bugger'. And then the following morning I can remember ((Mollie)) telling us, no problem at all. But then ((laughs)) later on again, another day, totally forgot what she'd said and how it worked again. […] So we got another microwave, didn't we? Simpler.*
Mollie	*Yeah, I got rid of; it was an all-singing, all-dancing microwave. […] So, all I've got is a £25 microwave now ((laughs)); one that you just turn. It's one that ((Anthony)) thinks he can use. We changed the cooker and did exactly the same thing now. [T1]*

Even where the person with bvFTD had less awareness, it still seemed that in the context of a previously positive relationship and an appreciation of the changes and the reasons for them, it was possible for family members to support opportunities to maintain selfhood. For example, as can be seen in Chapter 6, the Morris family hold a positive view of Bert and his value to them. They had also worked hard to understand the difficulties he experienced and explored ways of supporting him. Even though Bert appeared to have less awareness than some others participating in the study, he seemed to trust his family and accept the strategies they were putting in place to help and assist him (Table 7.22):

Table 7.22: Strategies to support selfhood	
Melinda	*So we try, as a family, to keep that routine and if Idris's taking him out for the day, or any of them are taking him out for the day, we start at the beginning of the week and we say, 'On Saturday we're going to do this,' and we count it down on the whiteboard and this helps.*
Bert	*Because Idris takes me out fishing, so I enjoy that for the day.*
Melinda	*He's really good with you. They're going to rebuild a motorbike once we can get a garage nearer, because we've got this one's motorbike, so you're going to rebuild that, aren't you? But because he's got no perspective of danger any more, he needs someone with him to do woodworking, even though we were just in the process of saying that there are powerless drills and things that we can look into getting him. So as a family, our next thing is to get him a workbench and start that way. But he does need people with him when he's using sharp things because he's got no sense of danger, have you?*
Bert	*No. [T1]*

In building on activities that Bert had previously valued, but making allowances for the difficulties he experienced, his family were able to explore ways of supporting Bert's selfhood.

However, where awareness is out of step between the person with bvFTD and the family and they have less understanding of the nature of the difficulties being experienced; this may have the potential to negatively influence selfhood. For example, as described previously in Table 7.4, Sue described more frequent arguments since Terry began to experience bvFTD. In this example it is possible that their conflict may have arisen in part because of Sue's lack of understanding of the effect of bvFTD and the possible strategies that they might use and therefore her positioning of him as at fault. Additionally, Carole, their daughter, who described a distant relationship with her father, also appeared to situate the responsibility for these problems with him, For example:

Jenny *So, when you go out with him and you're talking about his behaviour, how do you manage that?*

Carole *Just sort of laugh it off really, at the moment. It's not been anything too serious really that he's said. They're supposed to be coming tonight to Ruth's school play, so that'll be an interesting one. […] We'll just see. But I almost feel like I need to put him in a corner somewhere. He'll probably start talking to people. But I'll just have to deal with it really when it happens. [T2]*

Thus Terry's opportunities for maintaining selfhood may be compromised by the lack of understanding of bvFTD within the family.

A further element that may influence opportunities for maintaining selfhood was the self-concept of the person with bvFTD prior to the onset of dementia. For example, Bert experienced mental health problems earlier in his life:

Melinda *You're afraid of how people are going to treat you if you tell them, that's half your problem, isn't it? Because it's like Bert had mental health issues, he had a breakdown when he was 49, a really bad one and if you tell someone you've got mental health issues, the whole ... ((laughs)) the whole [conversation] finishes and people tend to shy away from you, so we've been dealing with that for a few years. [T1]*

Similarly, Terry also experienced mental health difficulties and also seemed to have had a difficult relationship with his family of origin, which appeared to have had an impact on his wellbeing (c.f. Chapter 6). Their fears about the stigma associated with mental ill health including dementia were evident in their narratives. It seemed possible that their prior experiences would have influenced their experience of dementia and therefore their self-concept.

It also seemed that for these participants, the impact of bvFTD on their ability to process external experiences and combine these with their internal world in order to maintain their well-being had a significant influence. This was clearly illustrated by Alistair and Terry (Tables 7.19 and 20). Aspects of daily living that were complex and multifaceted were difficult to achieve for all of

the participants with bvFTD. For example, Anthony likened his difficulty with processing, retaining information and communicating to being like a slow computer.

> *Anthony* *When you have a bad day it's [...] like a very slow computer: it takes so long to digest information. Even to speak you've got to search for the words, to try and find them before you can speak. So, it's very, very slow. [T1]*

Thus many aspects of everyday living could hold significant levels of anxiety for people living with bvFTD, when cognitive and emotional abilities are affected in this way.

Furthermore, their experience also seemed to be compounded by their awareness of the changes they are experiencing. The people with bvFTD who contributed to this theme experienced varying degrees of awareness of the impact of dementia. Where awareness was present it seems possible that this may have heightened their sense of insecurity. For example, Terry (Table 7.20) commented on the helplessness he experienced at his lack of ability to control the effect of bvFTD.

A further influencing element appeared to be the extent to which family members were able to comprehend the emotional world of the person with bvFTD. Where family members were able to recognise and understand the experience of insecurity and develop strategies then this appeared to have an influence on the person's experience of the world. For example, Kate recognised that Alistair needed emotional reassurance from her as a consequence of his difficulties (c.f. p151).

Alistair appeared to agree with her that her reassurance was important to him in combating feelings of insecurity brought about by his difficulties in functioning. Furthermore, Kate seemed to recognise that Alistair's capacity for processing emotions at a sophisticated level had changed. However, it did not appear that all of the families were able to consider the emotional world of the person with bvFTD. It seemed that being unable to consider how the person with bvFTD experiences the world may increase their sense of anxiety and frustration (table 7.23):

Table 7.23: Recognising the emotional world of the person with bvFTD	
Sarah	*This is just on a normal day, he was on the toilet and the trouble I have ((laughs)) is when I hear bad news, or someone shouts at me or something, my reaction is to giggle – I can't help it, it's just one of those things – […] So he's starting to get worked up and I just start laughing, ((laughs)) and it's obviously the wrong thing to do! So he gets worked up and we had it on the toilet the other day – Bob was here, […] and he had to come and help me because I can't lift him and Dad then gets the shakes and he pretends to cry, but it's not a pretend it's like Sarah 'Get me up!'*
Alex	*And he wails and it gets louder and louder.*
Sarah	*Yeah and he just goes into a complete panic mode.*
Alex	*It's almost like meltdown. [T1]*

In this example, Sarah and Alex described Ray's reaction to delays in supporting him. Ray seemed to become increasingly upset when his needs weren't met. While it appeared that Ray experienced some difficulty in coping with a delay in requests for help; it seemed that his response may also have been prompted by his experience of Sarah's reaction to him.

7.8 We're not the same anymore

Family members who were closest to and largely co-resident with the person with bvFTD, appeared to experience unique challenges. This reflected increased awareness associated with closeness that comes from living together or in one family regular and frequent contact. Therefore, while the impact of bvFTD was similar to that described in managing everyday life, it appeared that the effect on these relationships differed as a result of the closeness and the nature of the pre-existing relationship. Furthermore, the subtlety of the changes and the difficulty that others appeared to have in seeing these changes also influenced their experience. These changes are now discussed, considering how these family members perceived the changes that had occurred in the person with dementia and the implications this had for their relationship. '**We're not the same anymore'** was present for all five partners, one co-resident adult daughter and her husband and another adult daughter and her husband who were heavily involved in

caregiving. Narrative excerpts from all three time points contributed to this theme with three subthemes emerging from analysis;

- You're not the person you were to me
- You're the same but worse
- We're not the same anymore

A number of influencing elements were also evident including;

- Awareness – Unawareness
- Living together by choice/ increased contact
- Prior relationship
- The subtlety of the changes

However their influence appeared to be intrinsic to the subthemes above. Consequently unlike the previous sections, these influencing elements shall be considered within the discussions about each theme.

You're not the person you were to me

Six close family members contributed to this sub-theme (5 spouses and 1 adult child). All six had described previously positive relationships with the person with bvFTD (c.f. Chapter 6). As indicated previously, those family members in closest contact with the person with bvFTD appeared to have a greater level of awareness of the changes occurring than the person with dementia or wider family members who had less frequent contact. Indeed they were the first to notice changes in the person with bvFTD. All six of these family members suggested that the person had fundamentally changed as a consequence of their experience of bvFTD (table 7.24):

Table 7.24: You're not the person you were to me	
Melinda	*Yeah and it is very difficult losing the person that you loved and trying to learn to love the other person. Very, very difficult. […] I'm not going to get that Bert back. [T2]*
Sue	*There's no loving, we're more like brother and sister. […] [he] would never come up to me and give me a kiss or put his arms round me.[T3]*
Phil	*I'd get upset and she could see me upset but it'd still have no reaction and I couldn't understand that because that was never how she was. [T2]*

Mollie	*Anthony's as good a gold but he's always looking now for, "Shall I do this? Shall I do that?" or it's like, as I say it's like a child looking for approval, it's strange, whereas he used to be the one who would take control if you know what I mean [T2]*
Sarah	*You just think 'well. You're, everything that he was', he now is the contrast of, in my opinion. [T1]*
Kate	*But he's also a very lovely man. And that's the thing that's hard, when he gets unpleasant, because that's out of character. […] And that's just not characteristic and it's not the Alistair that I know. Well, it is the Alistair I know now. But it wasn't the Alistair I married. [T2]*

As the above quotes appear to suggest, many of the characteristics of the person that these close family members had previously valued were felt to have changed. Characteristics included those previously described, such as empathy, care and sensitivity to others needs. As indicated by Melinda in the quote above and previously in this chapter, she felt that Bert had lost the ability to be caring towards her and their children. Similarly others described changes such as unpleasantness and increased argumentativeness.

For example, Sarah appeared to feel that her father wanted to upset her, something she believed he would not have done previously. Although she acknowledged that they used to 'banter' she suggested that he no longer knew when to stop and could be very hurtful:

Jenny *So it used to be a banter but that's shifted?*

Sarah *We do still have a little bit of a banter but yeah he oversteps the mark a bit too much these days. What was the latest one? Oh yeah, his physio, who's a great friend of ours […] she's one of our best friends and we were on about doing something up the Wye Valley […] and she said, "Oh come up with me it will be great fun," and what did he say? She said, "We could have a canoe each," and he said, "Well that's all right for you, but Sarah's…" he didn't say fat and overweight but it was words along that line and that really cut and I was just like, no. And that did, but he was mean with it. So I just came away from there and I was in tears. [T3]*

Her husband Alex confirmed this and indicated that he had to call Sarah away at times to prevent these incidents occurring. As the above suggests,

disinhibition and lack of a social filter were therefore also found to be difficult by some.

Changes in levels of functioning also featured in these accounts. Kate, Mollie and Sue have referred to changes in abilities and skills earlier in this chapter. Such changes were evident in all seven family accounts. As the above quote from Mollie (Table 7.24) suggests, the nature of these changes is such that the person appeared to become increasingly dependent over time. Thus these close family members suggested that the person was less able to share in completing the everyday work associated with family life. The experience of loss at these changes was evident in the narratives of all six of these close family members, as demonstrated in table 7.24.

You're the same just worse

However Pamela and Jonathan Hugh, who were heavily involved in supporting her mother but were not living with her, held a different view of Elizabeth. This appeared to be as a consequence of their difficult prior relationship (Hugh Family c.f. Chapter 6). The death of Elizabeth's husband prompted an increased frequency of contact and engagement with Elizabeth's needs which continued following diagnosis and throughout the duration of the research. Although initially concern was expressed for Elizabeth due to the manner of Alfie's death, this increased contact appeared to become problematic due to the considerable difficulties Elizabeth was experiencing. These difficulties included spending significant amounts of money, drinking excessively and making decisions which had consequences for her own and other's safety as described earlier (Table 7.3).

While Pamela and Jonathan acknowledged some of the changes brought about by bvFTD they appeared largely to see them as exaggerations of Elizabeth's previous personality and behaviour. For example, in the following quote, Pamela had described her experience of her mothers' apparent perseverative behaviour regarding her jewellery. Even though both Pamela and Jonathan acknowledged that she had difficulty with planning, processing and memory and indeed with activities of everyday living, they didn't appear to have connected these difficulties with her mother's behaviour (Table 7.25):

Table 7.25: She's the same just worse	
Pamela	*And the problem is I don't like lying to her but you just don't know what to say because you just keep saying the same thing over and over again and you don't know whether she's taken it in or not and it just gets to the stage where you're thinking, 'I haven't got the energy to be challenged every time on certain things,' because you can go and everything's hunky dory and then all of a sudden she'll come out with questions and you're thinking, 'Oh I don't really want to answer this, because she's not going to be very happy with how I'm going to answer it,' because there aren't any right answers for them is there? It's all, well they just want to hear what they want to hear I suppose. They're just sort of like tuned into that aren't they? [T1]*

Consequently, they appeared to situate the problem with Elizabeth rather than as an outcome of the difficulties she experiences. Furthermore, they appeared to experience frustration with her behaviour and seemed annoyed at what they perceived to be unreasonable requests from her. For example, she had asked the gardener to do more work, without recognising the consequences for her finances. Pamela and Jonathan seemed upset with her, without recognising that she might have difficulty comprehending the limitations and therefore positioned her as the problem:

Pamela *She just manipulates people into doing things and they're just very clever at doing that aren't they?*

Jonathan *I don't think that's any different I mean she's always done that.*

Pamela *Yeah I know but it's worse now. [T1]*

Her apparent lack of awareness of her condition also appeared to be a further source of difficulty for them:

Jonathan *She will get upset because she won't accept that there's anything wrong and she won't accept there's a need for the care that's been put in place and that there's a need to say no. she just won't accept that and it upsets her doesn't it? [T1]*

Their positioning of her as the problem continued throughout the duration of the research.

We're not the same anymore

The impact of these changes on partners and adult daughters and their husbands seemed to be different, so are presented separately here.

Partners

The changes described above and in the previous section (p.156-66) had a profound effect on the relationships that partners experienced with the person with bvFTD. Nevertheless, in spite of the significant changes, a continuing bond was evident in the majority of narratives:

> *Melinda* *And it isn't the Bert we know and love but it's me trying to learn and get to know this new person that the kids say "It's a new dad." [T1]*

Furthermore, supporting the person with bvFTD seemed to be an accepted part of their commitment to each other:

> *Mollie* *We always said that if one of us become unwell the other one will look after. [T2]*

Taking responsibility for the person appeared to have become a feature of everyday life for the majority of the spouses. This level of responsibility involved caring for the emotional and psychological well-being of the person as well as managing activities of daily life and self-care needs. For example, in the quote above (Table 7.24), Mollie likened Anthony's responses to that of a child. She goes on to explain this further in another interview:

> *Jenny* *So are there other ways that it's changed how you are together?*
>
> *Mollie* *I find that I'm more caring, carer, as long as he's all right. I'm like…I think of Anthony like I think of my grandchildren, you know, as long as they're all right I've got to make sure they've got to be okay, he's okay. [T2]*

This representation of the way of being of the person with dementia also seemed to feature in other partners' accounts. As has been highlighted in this chapter, complex changes occur in emotional and cognitive sophistication arising from the effect of bvFTD on executive function and social cognition. It seems possible that the characterisation of the person as childlike represents the only reference point that partners have to explain such a complex process. As a consequence, the relationship between four of the married couples appeared to have shifted from one of partners to one in which the spouse felt they were taking total responsibility for the person and for their needs. Indeed Kate described having to think for Alistair before they received his diagnosis and increasingly took responsibility for him and their lives together throughout the duration of the research:

Kate *I knew I was…despite the fact that we hadn't got a label for what was going on I knew I was taking more of the thinking for both of us on […] [T1]*

Kate *Everything is my responsibility […] [T3]*

There appeared to be consequences of this change for some partners in regard to the intimacy in their relationship. While for some, changes in intimacy arose directly from the effect of bvFTD:

Jenny *And did you notice a change in your relationship over the time?*

Phil *I mean, if you're talking about real personal relationships, well it just fizzled out and died about seven years ago. No interest. She's got no interest. No interest basically. [T1]*

Other partners related this to the change in the nature of their relationship (Table 7.26):

Table 7.26: Changes to intimacy as a consequence of caregiving	
Jenny	*I guess one of the things I'm conscious of is that sometimes people talk about the impact it has on their own relationship in that sometimes people feel that there's not a recognition of each other's experiences and feelings. And I wonder whether you feel that that's true for you, or whether you...?*

Anthony	*To a certain extent it is.*
Mollie	*Yeah. I feel I'm more carer. I feel that I've got to look after Anthony more than a wife in some respects. I think he knows what I'm talking about. So I think as far as man and wife... They keep saying "Oh, will you continue marital relations?" or whatever, but in your mind is, you think "That person has got dementia. He's vulnerable. Is this right or is this wrong?" He knows what I'm talking about I think.*
Jenny	*So it sounds as though it's changed the way you think about...*
Mollie	*Yeah. And I think that's been since Anthony was diagnosed with dementia. I think I've read too much on the internet to be honest. Because people can be vulnerable, they can be... Somebody with dementia is a vulnerable person. You still go to that person to make love, if you know what I mean, or do you, you're looking after that person. And that's what's in my mind. I don't think it's in his. Because I'm looking at myself more as a carer. And I'm always conscious, "Is he alright?", "Have you got your tracker?", "Are you okay?", "Have you eaten your breakfast?", "Come on, you've got to eat your greens." I'm looking at that more than anything. And I know it's impacting on Anthony. I know he feels it, because he told me. But I can't get my head round it, the fact that I'm still looking after him. [T3]*

As Mollie described, she found it difficult to contemplate intimacy when her relationship with Anthony had changed so fundamentally from wife to carer. Nevertheless, the implications of withdrawing from this aspect of the relationship were significant in terms of the losses experienced as suggested by Kate:

Kate	*Alistair is still functioning, [but] it didn't feel right," […] And we both want it to be but I just can't it's just not right, I just can't do it. [T1]*

As well as the need to take responsibility for the person, changes to social cognition also impacted on the way that partners perceived the relationship with their spouse. The effects of changes to social cognition were described earlier in the subtheme managing everyday life and apply equally to the

relationship between partners. As described previously, changes commonly affected difficulties with empathy 'in the moment'. Kate had previously described how important Alistair's thoughtfulness and empathy was to her and to their relationship (c.f. Chapter 6) consequently the change appeared to be significant to her in viewing their relationship as fundamentally altered. Indeed she subsequently commented on feeling that she was mothering Alistair:

Kate *I think it's more like…I tend to be more mothering, yeah more mothering. It's because we went through like the brother and sister bit, Alistair was still my friend, I could still confide and talk to but because there's no empathy there isn't that same sharing of jokes, of information and because so much more responsibility is mine now for simple decisions like the car, the fence, all of it tends to be mine, I feel more as if I'm mothering than I […] [T3]*

Changes in reciprocity were also described by a number of partners. For example, Sue suggested that she and Terry had always helped each other and gave an example of doing the shopping together because of the pain she experiences. However she seemed to feel that he was no longer as attentive as he had been in the past (Table 7.27):

Table 7.27: Changes in reciprocity

Sue	*We nearly always end up when we've been shopping having an argument... well I do because we don't do it together anymore. You see what we do we go to Aldi because I can cope with that it isn't such a big store. Sainsbury's is so big and my neck I'm in so much pain by the time I've gone all up and down these aisles, […] But Terry, "I'll go and get a paper from Morrisons" so I say, "Okay, right I'll see you in the store." So I start doing my shopping. And eventually he does come and he comes to the trolley and he puts something that he wants in the trolley and then he...*
Terry	*How dare you.*
Sue	*And then [he's] off again. And I end up at the checkout and I'm putting all the things on then I have to put them all back in the*

	trolley don't you in Aldi. And eventually he... Yesterday he came and he put the last two items and I thought oh thanks Terry two loaves of bread. ((laughter)) [T1]

In the above quote, Sue referred to the difficulties she experienced with managing shopping due to her pain. She needed support from Terry to complete this activity and described how much this had changed, indicating that effectively she now felt alone when undertaking shopping. As their relationship appeared to be founded on mutual support and assistance (c.f. chapter 6 Stuart Family) Sue appeared to feel this loss keenly.

It therefore seems that due to the nature of the relationship between couples, expectations of relational exchanges such as empathy, intimacy and reciprocity, particularly where this was the norm in the relationship, appeared to result in the changes assuming greater significance for these partners. The challenge in this regard also seemed to be related to the proximity and possibly the intensity with which these changes were occurring. Furthermore, given the significance of communication in relationships, it also appears that changes in communication contributed to the belief that the relationship had altered. For example, Mollie and Phil described communication changes with their partners (table 7.28):

Table 7.28: changes in communication

Mollie	*Before he went on Sertraline he was beginning to shut down for long periods. What I call his 'sit in the chair and just go very quiet'. Unless you spoke to him he wouldn't speak. Just didn't want to communicate. And it was getting worse and worse. So it was beginning to affect me as well as him, […]*
Jenny	*Right. And you were just saying that it had started to affect you as well. In what way?*
Mollie	*Yeah. Because he's so quiet. Well, I turn the radio on in the kitchen, I turn the radio on in here. Just to have a noise. Because there was nobody to talk to, because he was just going so down. And you try and talk, "Yes.", "No." And that's all you were getting. [T3]*

Phil	*At least five or six years. Well you couldn't sit down to her, you're watching the TV and discuss a TV programme. You couldn't discuss the political situation, where she's always been very pro that in the past. You couldn't discuss the effects of the recession on people's scenario at all because she just wouldn't be able to participate. She wouldn't understand where she was or what it was all about. [T1]*

Both quotes emphasise the relational consequences of these changes, including the loss of everyday conversation as well as stimulating discussion.

Finally, it appeared that as the person's needs increased, opportunities to spend time apart as well as together became more of a challenge:

Sue	*because we're never really apart, you see. He even wants me to go to the shops with him.[T2]*

Other partners also shared this concern, particularly when the person with bvFTD appeared unaware of the risks associated with their actions. As described by Phil (p.163-4) this ultimately resulted in him not being able to leave Penny on her own at all, unless he had carers to support her.

However, one of the partners rarely referred to taking responsibility for the person with bvFTD, possibly because she had always directed the relationship. Her daughter Carole suggested that her mother had always told her father what to do and therefore seemed to feel that this was just an increase in pre-existing aspects of their relationship:

Jenny	*How do you think she is with him?*
Carole	*Frustrated, I think. I think that would be a good word to describe them at the moment. Because she's with him all the time, so it's constantly repeating the same stuff to him and having to organise him and tell him what to do. Which I suppose has always been their relationship, but it's just more at the moment. And I've said to her "You'll have to tell him if you need him to do something he won't. Just think, to hold your arm, to steady you, you'll have to say to him "Terry, wait for me." That's the only thing, really. [T2]*

Therefore, it is possible that Sue did not refer to this in her narrative because it is the norm for their relationship from her perspective. However, as the above quote suggests, it also appeared that Sue struggled to recognise the impact of bvFTD on Terry's ability to engage with what she needed him to do.

Daughters and their husbands

The two adult daughters and their husbands who were caring for their parents had similarities and difference in their experiences, thus attention is given to both in this discussion.

As can be seen from chapter 6, Pamela and Jonathan Hugh described a sense of surviving together without Elizabeth's support. Indeed they appeared to have found it necessary to maintain a distance in their relationship with her and closeness was equated with feeling 'sucked dry'. Furthermore, as discussed above, they felt that bvFTD had exaggerated aspects of Elizabeth's personality and behaviour rather than changing her, therefore they positioned her as the problem rather than the dementia. Pamela felt a sense of duty to care for her mother when she and Jonathan initially realised the extent of her difficulties. It appeared that this sense of duty continued throughout their involvement in the research:

> *Pamela* *So then you wonder why are we doing all this support for my mother but I think it is possibly the upbringing really you just feel that you have a duty that you should do it really […] So therefore I suppose the responsibility I feel as though I've been landed with that responsibility. [T1]*

However Pamela did not appear to welcome caring for her mother. She and her husband Jonathan seemed to feel compelled to take control as a consequence of her risky behaviour and provide significant levels of support (c.f. Table 7.13). Nevertheless, they felt that this was an undesired shift to a greater level of contact and responsibility for Elizabeth than they were prepared for. Furthermore they appeared to feel that her lack of insight and awareness of her condition or indeed appreciation for the level of support that they offered further damaged their relationship:

Pamela *And when I went there a few weeks ago, she sat there, having a cup of tea, her friend phoned her, she ignored me, she didn't even ask me if I wanted a drink. It was as though I was invisible. [T2]*

This resulted in the further deterioration of an already difficult relationship, as described by Pamela at time point three:

Jenny *Mm so how do you think your relationship with your Mum has been affected?*

Pamela *I haven't got one. It sounds awful but I don't want to see her, I don't want to do anything for her. [T3]*

However, it appeared that Pamela and Jonathan felt unable to change their level of involvement and free themselves of their contact with her because neither her family nor professionals were willing to take over:

Pamela *And I said "Look. If you want to change the care, you carry on. But you will take the responsibility." I said "I'm not taking the responsibility." I said "We're sitting here, round this meeting and I don't want to do any of this. I don't want to do the finances, I don't want to do the care, I don't want to be the one responsible. I'm the kicking-person. I don't want to do it!" […] It was just so awful that day. I said "Oop, what a surprise, no one wants to take it off." ((laughs)) Because nobody will. [T2]*

Pamela's sense of indignation and frustration with the situation seemed evident in her tone of voice during this narrative. She subsequently explained that she wished her mother would die:

Jenny *So what would you like to see happen now?*

Pamela *A natural death ((laughs)) sooner rather than later. [T3]*

It seemed that ultimately this was the only way that they felt they would be free of the burden of caring for her. Therefore, it appeared that the boundaries they had valued in their relationship with Elizabeth had been

undermined by her need for care which had caused their relationship to deteriorate further.

Sarah and Alex's narrative about their relationship with Ray seemed to be different, in as much as Sarah described a positive relationship with her father before he began to experience bvFTD (c.f. Chapter 6). Consequently, Sarah experienced similar challenges to those of the partners of people with bvFTD in regard to the sense of loss and distress at the changes in him (c.f. Table 7.24 and p.184). Having moved back home prior to Ray's diagnosis of MND, Sarah described a period in which their relationship strengthened and it appeared that her motivation to care was grounded in this pre-existing relationship:

> *Jenny* *So it's been a big change.*
>
> *Sarah* *Oh yes, yeah, but he's my Dad, so, at the end of the day, it's payback time, isn't it! ((laughingly)) [T1]*

However in common with the Hugh family, Sarah did not always link the changes in her father to the symptoms of bvFTD and found his behaviour frustrating. Consequently, Sarah and her husband Alex also positioned Ray as being responsible for his behaviour, rather than recognising that it might be influenced by dementia. Furthermore, they seemed to feel that he had control over his behaviour and could be different if he wanted to be:

> *Sarah* *But then we know that he can put on and be really good and have a really decent conversation, so then I suppose that angers me in a way, because I just think, 'Why can't you do that with us?'[T1]*

As a result, Sarah and Alex appeared to feel that the relationship they had with Ray had deteriorated over the duration of the research. At time point one, Sarah suggested that Ray had fundamentally changed and implied that he would never have been as argumentative and self-focused as he was now:

> *Jenny* *So how has he changed, what's he like?*
>
> *Sarah* *Oh, he's very argumentative now and he never used to be, everything's all about him […] You just think well you're,*

everything that he was, he now is the contrast of, in my opinion. [T1]

Sarah appeared therefore to feel that their relationship had also changed fundamentally (Table 7.29):

Table 7.29: I'm more carer than father / daughter

Jenny	*How has that changed because you said you've become more of a carer than a father/daughter, can you tell me in what way you think that's changed.*
Sarah	*Not that I'd go to Dad for advice anyhow but I wouldn't go to him for advice now whereas sometimes you just think, 'Oh it would be nice to'. Yeah we're just getting through the day by doing the necessities with him, so eating, drinking, toiletries, rather than, yeah, taking, yeah him doing anything for me because ((laughingly)) he doesn't ever, except wind me up and he likes doing that, mm. [T1]*

Subsequently she described having lost respect for her father because of his behaviour. Furthermore, it seemed from their perspective that Ray's lack of awareness of the impact of his behaviour on them also seemed to be a source of difficulty. Over time, there appeared to be a lessening of the sense of frustration in their tone of voice when describing Ray's behaviour and on occasions a recognition that his behaviour may be as a result of his diagnosis:

Jenny *Why do you think he's like that that he needs routine?*

Alex *Everything is beyond routine isn't it? It has to be just so.*

Sarah *I always thought it was the condition.*

Alex *Yeah the dementia side of it.*

Sarah *So never really, yeah because he never used to be. [T3]*

Nevertheless their relationship continued in the main to be poor. For example, Sarah appeared to feel at time point three that she needed to avoid Ray in order to survive the situation, even though she acknowledged that this was not always the right thing to do:

Sarah *I tend to avoid him. […] the carers come in from half six, quarter to seven and then until quarter to eight so I just leave, that's my time upstairs […] I come down about quarter*

to eight, […] and I walk through past him and get to the kids and then think, 'Oh I haven't even said hello to dad.' And I think that's mean. I don't mean to and I'm like, "Are you all right dad? How's it going? All sorted this morning?" and sometimes he doesn't even acknowledge me, well I've obviously ignored him but […] [T3]

While struggling with Ray, she and Alex appeared to try and balance their frustration with the recognition that Ray had lost a lot and that they should therefore be more understanding. Similarly, they appeared to value the relationship between him and their young children and seemed to want him to stay at home and to be well in order that the children would have a memory of him as their granddad:

Alex *This has been my biggest wish since we've had the two little ones is he stays around long enough that they can have a proper memory of Granddad.*

Sarah *Yeah.*

Alex *That's my biggest wish I just hope that he can cling on as far and as long as he can, another ten years, whatever, but just so the kids have got a proper memory of Granddad not just me and Sarah saying, "He absolutely doted on the pair of you." [T2]*

Therefore, for Sarah in particular, their relationship was no longer the same because Ray had fundamentally changed from the father Sarah appeared to believe she previously had. Nevertheless, she did not appear to be as desperate for the relationship to end as seemed to be the case for the Hugh family.

7.9 Chapter Summary

Four challenges appeared to be present for these seven families;

- Awareness and understanding of the changes
- Managing everyday life.
- Being me in the context of bvFTD
- We're not the same anymore.

Awareness and understanding of the changes

Awareness and understanding of bvFTD appeared to be variable within all seven families and occurred at a different pace for those closest to the person with bvFTD than for those who had infrequent contact and/ or were not as emotionally close. Furthermore, it seemed that there were some who denied that changes were taking place or who had not able to make the transition from awareness to understanding. Some families appeared to have been able to work together to understand what is needed whereas it seemed that for others a lack of a shared understanding caused distance and disconnectedness between family members.

Awareness and understanding of the family appeared to be influenced by the awareness of the person with bvFTD, with their awareness increasing opportunities for collaboration. Availability of supportive and knowledgeable professionals appeared to be important to support the transition from awareness to understanding.

Managing everyday life

All seven participating families appeared to suggest that bvFTD had a wide ranging impact on wellbeing, relationships, activities of daily living and other aspects of family life. Reductions in features of social cognition and executive functions appeared to impact upon relationships with wider family members. Some participants with bvFTD appeared able to reflect on their behaviour and its impact in relation to specific incidents or experiences. However, it appeared that their capacity to respond empathically ‘in the moment’ was significantly affected. These difficulties appeared to have a substantial impact upon everyday social interactions, thus providing many challenges to everyday life. Furthermore, bvFTD appeared to impact on judgement, decision making, planning initiation and monitoring therefore affecting the ability to undertake activities of daily living and self-care. This appeared to result in family members taking increasing levels of responsibility for these activities and ultimately for the person themselves. Difficulties appeared to progress over time and as a consequence, supervision and care needs increased to ensure safety and wellbeing.

This subtheme was influenced by awareness of family members and the availability of supportive professionals. Furthermore, knowledge of similar difficulties and contact with knowledgeable others such as peers also appeared to influence how families responded to the impact of bvFTD on everyday life.

Being me in the context of bvFTD

The challenge of being me in the context of bvFTD appeared to be experienced by all five people living with dementia who participated in this research. People living with bvFTD seemed to experience challenges to self, identity, agency and safety in the context of the social and cognitive changes brought about by dementia.

All five participants living with dementia experienced varying degrees of awareness of the effects of bvFTD on their cognition and their behaviour. Some were also aware that this affected others including wider family. However, there appeared to be a lack of emotional engagement with the impact of the changes for them or for others. In those who were aware, it appeared that levels of awareness deteriorated over time. It seemed that some recognised and accepted that others including close family were more aware of the extent of the changes than they were. The changes brought about by bvFTD appeared to have the potential to impact self-concept and identity.

Furthermore, bvFTD appeared to compromise their ability to process external experiences and combine these with their internal world in order to maintain their well-being. This appeared to influence their security, safety and sense of control over their everyday lives throughout the duration of the research. Holding to routines, familiar places and people were used to combat these feelings. However, it seemed that for some, panic and distress were significant consequences of feeling out of control, unsafe and insecure. It seemed that family members could influence these feelings if they had understanding of the person's emotional world.

We’re not the same anymore

Five partners, 2 adult daughters and their husbands appeared to experience significant changes in their relationship with the person with bvFTD. Six of the seven family members appeared to suggest that the person with dementia had changed fundamentally, with bvFTD affecting many of the features that they valued about the person previously. These included aspects of social cognition such as empathy, care for others, willingness to recognise others needs and gentleness. They also described changes in their ability to function independently and therefore to share in the work of everyday family life. Loss and grief at these changes appeared to feature in these accounts. Conversely, one adult daughter seemed to feel that bvFTD had exaggerated previous personality characteristics, although this occurred in the context of a previously poor relationship and limited awareness and understanding of bvFTD.

Therefore changes to relationship were evident in all 7 accounts, although there were differences for partners and for adult children. Many of the partners appeared to take on increased responsibility as a consequence of the changes in the emotional and cognitive sophistication of the person with bvFTD. Partners’ accounts appeared to suggest a loss of many of the valued aspects of their relationship, including empathy, intimacy, mutual support, reciprocity and communication. Awareness and understanding appeared to have an influence on how these changes were constructed. Both adult daughters appeared to experience changes in the relationship and also shared limited understanding of the impact of bvFTD. However, their relational history appeared to influence how they perceived this change and its meaning for them. A previously poor relationship seemed to give rise to conflict and a sense of entrapment for one adult daughter. In contrast, a previously positive relationship appeared to result in a significant sense of loss in the other adult daughter which in turn seemed to give rise to difficulties in adjusting to the changes in her father.

Chapter Eight: coping processes used by families to address the challenges brought about by behavioural variant frontotemporal dementia (bvFTD)

8.1 Introduction

In the previous chapter, I have presented the results of a grounded theory analysis which identified psycho-social, cognitive, behavioural and relational challenges brought about by bvFTD for participating families and for individuals within the families, including the person with bvFTD. Two challenges related to the experience for the whole family, **awareness and understanding of the changes** and **managing everyday life**. A further challenge related directly to the experience of living with bvFTD for the person with dementia; **being me in the context of bvFTD**. A final challenge related specifically to partners or adult children who were living with or heavily involved in supporting the person with bvFTD; **we're not the same anymore**. Furthermore, I explored a range of influencing elements as these impacted upon the experience of these challenges.

In this chapter, I present the coping processes used by individuals and families, to address each of the challenges. Families and individuals appeared to develop coping processes which ranged on a continuum from assimilation and adjustment, through to resisting the diagnosis and the associated changes. Consequently I have identified a superordinate theme; **Assimilating, adjusting, reconstructing --- Resisting, denying, being stuck**. Themes connected with this continuum, which are specific to each challenge, emerged from analysis. These are presented in table 8.1:

<table>
<tr><th colspan="4">Table 8.1: Coping processes used by we/ I</th></tr>
<tr><td>Superordinate Theme 2: Challenges to we/ I:</td><td colspan="3">Superordinate Theme 3:
Assimilating, Adjusting Reconstructing -------- Resisting, denying being stuck</td></tr>
<tr><td>Awareness and understanding of changes</td><td colspan="3">Accepting and Assimilating
It's dementia, we have to find a way through this

Resisting and Blaming
Resisting knowing
They are the problem
You're the problem, you don't work with us or help us
Distancing</td></tr>
<tr><td rowspan="2">We're not the same anymore</td><td>Accepting and Adapting
Accepting the changes and finding new ways of being together</td><td>Fighting
Resisting the changes we're going to fight this together</td><td>Distancing and being stuck
Achieving Distance
Being stuck</td></tr>
<tr><td colspan="3">Accepting the need for a changing I
• Grieving for a changing you and a changing we
• Acknowledging the need for a changing I
• Accepting the need for a changing I</td></tr>
<tr><td rowspan="2">Managing everyday life</td><td>Enabling and Facilitating</td><td>Distancing, Managing and Controlling</td><td>Avoiding and Reacting</td></tr>
<tr><td colspan="3">Underpinned by Collaboration, Adaptation, Communication, Addressing Conflict and Cohesion</td></tr>
<tr><td rowspan="2">Being me in the context of bvFTD</td><td colspan="3">Maintaining Self:
o I'm still me, still active and engaged with life
o I'm still me there's nothing wrong
o I'm still me, resisting negative perceptions</td></tr>
<tr><td colspan="3">Maintaining Wellbeing:
o Supporting safety and security (a collaborative process)
o Holding them (family members)
To
o Resisting and restricting (person with bvFTD)
o Controlling, positioning and distancing (family members)</td></tr>
</table>

As acknowledged in the previous chapter, the coping processes used by the families are similarly multifaceted and complex and appear to have a reciprocal influence on each other. Thus there are close connections between sections in this chapter and between this and other chapters.

8.2 Awareness and Understanding of the Changes

In chapter seven, the challenge of awareness and understanding of the changes associated with bvFTD was discussed. The coping processes used by families and individuals are now discussed. Each of the participating families coping processes can be positioned on a continuum from **accepting and assimilating --- resisting and blaming.** A number of subthemes appeared evident from analysis as follows;

Accepting and assimilating

- It's dementia we have to find a way through this

Resisting and Blaming

- Resisting knowing
- They're the problem,
- You're the problem, you don't work with us or help us
- Distancing

Accepting and assimilating

As described in Chapter 7, it appeared that moving from awareness to understanding was an important step in enabling families to develop coping processes that addressed the impact of bvFTD on their lives. The Morris and Perrin families appeared to have well established patterns of collaboration and communication within family relationships (c.f. chapter 6 and p.144-5). Both families described collaborating to address the challenges brought about by bvFTD. Collaboration involved developing a shared understanding of the challenges facing them, seeking to understand the emotional world of the person living with bvFTD and learning about bvFTD in order to develop appropriate responses. For example, members of the Perrin family described their approaches to addressing the challenges they faced (Table 8.2):

Table 8.2: Collaborating, learning, putting yourself in their shoes	
1 2 3 4 5 6	**Kate**: And so we were chatting about what had gone wrong this week and why, so we were able to do that, which I think is what holds us together really. **Jenny**: Is that something that you do quite a lot? **Kate**: We've always done. […] We all sit down and we all talk about it, whatever it is, we've always done that. And we've always made a point that everybody ate tea together so that everything was shared.

7 8 9 10	**Alistair**: Yes. **Kate**: So that is new, the talking about stuff through isn't new. **Alistair**: Isn't new, no. **Kate**: We've always done that. We think out loud, we plan out loud. [T1]
11 12 13 14 15 16 17 18 19 20	**Rachel**: I think we all are good at asking him to try. So the one strategy my mum put in very early on was treating it like a brain damage, so making him think of the answer. So if he tries to answer like, "I don't know," it's like, "Well try," because sometimes you know he knows and he's just saying, "I can't do it," and he'll say things like, "I can't help it," so "Yes you can try," and because my mum does that I started doing it and my sister does it and I've noticed that my grandmother does. I've not ever heard my grandfather say it but I know my grandmother's sort of started to make him think and I think that definitely helped when my mum was doing it so I think the fact that more people are actually making him. And I'm aware of the fact that he's trying more now. [T2]
21 22 23 24 25 26 27 28	**Rena**: And then my cousin in Ireland has a husband who is quite a bit older than her and who has Alzheimer's and Tessa has been through a lot with Arthur. Arthur's now 86 and is at home and sort of being cared for but doesn't really know which side is up. And she had read this book that she said Kate should read. Well by this time I was a bit scared to say to Kate, "Tessa wants…" So all I did was email, I just forwarded it to Kate from things that Teresa had said. Anyway Kate did get the book, much to my surprise and we both read it. And that did change how we viewed…how to deal with Alistair. [T1]
29 30 31 32 33	**Rena**: And he doesn't often show his…the sad side to us. We were in France one night, a year or so ago I suppose and Dave had gone to bed and the three of us had sat round having yet another glass of wine and Alistair sort of started to talk and opened up a bit. And I realised that it was much harder for him than we see. [T2]

In lines 21 to 28, Rena describes their ability to learn as a family and take on new information to help them to cope with the changes Alistair was experiencing. This appeared to be achieved through collaboration across generations. For example, in lines 1-28, there are many references to working together as a family to address the challenges. Even though collaborating could be difficult (lines 25-27) it seemed that the Perrin family were able to find ways of communicating to develop a cohesive approach. They were also able to consider what it might be like for Alistair. Even though there was evidence in this family of different levels of awareness, (c.f. chapter 7, p.147) they nevertheless appeared to accept that it might be difficult for Alistair (lines 29-33). Alistair also seemed to collaborate in this, agreeing with Kate that they talked things through (lines 8-10). Furthermore, even into time point three, he appeared to recognise that the coping

processes they had developed were supportive of him and he valued his family's support. For example, he described the support that Dave had offered him:

> *Alistair* *It's a challenge to get myself motivated to go and do more on my own. If somebody comes round and says, "Come on we're doing this," then it's not a problem. [T3]*

As described in chapter 7 (p.154-5, 167-8) the availability of knowledgeable others was an important element influencing their approach. Members of the Perrin family made reference to knowledge gained from others, in this case Rena's cousin (lines 21-28). Furthermore, in Rachel's discussion, she referred to the brain injury approach (lines 11-20) that Kate had described as a strategy she had developed in part through her contact with a friend whose son had traumatic brain injury.

Similar approaches are evident in the Morris family, as can be seen in chapter 7. They described learning from knowledgeable professionals in order to understand and consider how to help Bert (table 7.9). Furthermore they valued the opportunity to learn from others in a similar position to themselves (Table 8.3):

Table 8.3: learning from others

Bert	*Talking about problems that they'd had, that... They'd gone through and sorted out and then little did we realise that we'd be going through the same, not exactly the same, different things and ending up with the same problems. […]*
Melinda	*I think it was like, you'll go through sessions where you never stop talking. And then you don't speak for a long time. And speaking to a couple of the gentlemen there, they were experiencing the same and it was like a cloud had lifted off you, wasn't it. Because it's knowing that that is part of it. [T2]*

The Morris and Perrin families moved from awareness to understanding once diagnosis had occurred. Even though there were differences in levels of awareness within the family, these appeared to be accepted and did not prevent them from collaborating to address the challenges brought by bvFTD.

This approach continued throughout the duration of the research as new challenges and changes emerged. For example, Kate explained that their dance teacher had died; consequently they wanted to find a way of keeping on dancing. Attending another dance class would have been difficult for Alistair as he didn't like strangers or new places therefore Kate identified another way of addressing this:

> *Kate* *But I think I've found a solution, […] so I've hired the village hall every Tuesday night, […] and then we'll just walk our way through the steps and I've worked out and I'm going to make some posters so that there's a visual clue for Alistair as he's dancing round and we'll just use the village hall as a practice […] [T3]*

As the above quote highlights, Kate sought to recreate the lessons they had received in a safe environment. Furthermore, her parents and other friends who had attended the lessons joined in with this.

In the Burton, Lewin and Hugh families, collaboration occurred within subsystems in each family, between the person with bvFTD and their partner or between couples involved in caring for the person with bvFTD. For example, as described previously in chapters 6 and 7, Mollie and Anthony Burton had a close relationship and did not appear to see wider family as central to their lives together. As a couple, they appeared to work together closely to understand and cope with the impact of bvFTD and used similar coping processes to those described above. In attempting to understand the changes taking place and consider how to manage them they described reflecting at the end of each day:

> *Jenny* *One of the things I wondered about was what helps you to cope now? What are the things that help you to cope and to manage the challenges that this brings?*
>
> *Anthony* *My coping strategies are ever so good […]To a certain extent we do tend to analyse the day at the end of the day as to, you know, how the day's been, you know and…*
>
> *Jenny* *Is that both of you or…*

Mollie *Mm we usually sit and have a chat about it don't we?*

Anthony *Yeah.*

Mollie *What's gone on throughout the day. [T1]*

However collaboration and communication did not extend to wider family members. For example, while Jane visited regularly, it appeared that this contact did not include working together with Mollie to support Anthony. Rather it seemed to be about her visiting to maintain contact with her father, during which she was sometimes informed of changes:

Jenny *So how have things been since then with your dad?*

Jane *Okay. I think he's gone downhill maybe slightly from what Mollie's been saying to me. But he still seems quite happy in himself and he still remembers who I am which is nice. [T2]*

Thus collaboration and cohesiveness only occurred between the couple in this family. In both families where adult daughters were caring for their parent, there appeared to be some collaboration between the adult daughter and their partner. For example, Sarah described at time point two and three, that she and Alex had needed to come together to cope with the challenges:

Jenny *I was aware from the discussions that we were having that there was quite a lot of frustration on your part around how he was behaving and how you were trying to deal with it and I just wondered whether you felt things had changed a bit in that way?*

Sarah *I think we've addressed it and I think Alex and I just work better now as a team. We try not to let anything stress us out.[T2]*

However it also appeared that this had its limits and Sarah acknowledged that in spite of their need to work as a team, she found it difficult to hear Alex criticise her father and would defend him when Alex raised issues with his behaviour. Neither of these couples had experienced collaboration with professionals concerning their parents' experience of bvFTD. Indeed the Hugh family in particular seemed to experience an adversarial relationship with professionals who they suggested lacked knowledge and understanding

(c.f. p.154-5). Similarly both struggled to make the transition from awareness to understanding. It is with this in mind that I now consider the opposite end of the continuum, that of resisting and blaming.

Resisting and Blaming

In four of the families (Burton, Hugh, Lewin and Stuart families), some family members seemed to have struggled with understanding the difficulties experienced. Consequently the coping processes of those who resisted or denied the difficulties involved positioning the problems with the person (Table 8.4):

Table 8.4: Positioning of the problem with the person with bvFTD

1	**Alex**: But he doesn't see that, he thinks we're his carers full time whatever
2	[…] I think now. I think it's got to that stage where it's, "Just do it." […] Not a
3	case of, "Could you, would you mind?" it's a case of, "Get and do it."
4	**Sarah**: And he goes on about, "Oh when I was younger I used to do this and I
5	used to do that," and whatever and, "Life has changed and these youngsters
6	don't do it," and whatever, well I think he's only on about us but then if we go
7	and say, "Oh we're going out," or we've got this on or we've got that on. […]
8	"Why?" and he doesn't like it.
9	**Alex**: So if we'd got somewhere to go he wouldn't be happy.
10	**Sarah**: If we've got a party to go to then no he doesn't… "Where are you
11	going? How long are you going to be?"
12	**Alex**: That's right and if that's the case just when we're about to go he'll want
13	the loo.
14	**Sarah**: Oh yes.
15	**Alex**: Spot on.
16	**Jenny**: Right.
17	**Alex**: That's clued up that is, that's not…it's almost like, "But I know how I can
18	keep you here a bit longer." [T2]
19	**Pamela**: We can't do anything, you know, it was so bad and she was so
20	resentful towards us that we couldn't do anything.
21	**Jonathan**: And we have tried to look at it from her point of view. It's very
22	difficult to understand obviously because we don't know how we'd feel but the
23	sympathy can only go so far because when someone just will not accept what
24	you're trying to tell them in their best interests however understanding you try
25	to be its very frustrating. [T1]

In the above examples, Sarah and Alex (lines 8-18) and Pamela and Jonathan (lines 23-25) appeared to see the person's behaviour as deliberate and intentional. Both also appeared to experience frustration and anger with the person with bvFTD (lines 1-18, 21-25). This was also evident in

their tone of voice when describing the actions of their parent (c.f. chapter 6, research context). For both of these families, it seemed that a consequence of this was that relationships with the person with bvFTD deteriorated. By time point three both Sarah and Pamela described avoiding contact:

Sarah *I tend to avoid him. […] [T3]*

Pamela *But I've not been round as regularly as I could have done ((laughs)) because I just can't stand it really, […] [T3]*

While by time point three, Sarah and Alex seemed to appreciate to some degree that Ray's behaviour may be as a consequence of bvFTD, it did not appear that Pamela and Jonathan were able to shift to this position. Indeed as described in chapter 7 (p.194) Pamela saw her mother's death as the only resolution to their caregiving responsibilities.

Sue and Carole Stuart also appeared to position Terry as being at fault (c.f. table 7.4 and p.179-80). A consequence of this for Sue and Terry seemed to be an increase in conflict within their relationship even into time point three:

Terry *If I was aggressive, I would say yes, I'd have something done about it, but I'm never aggressive, am I?*

Sue *Yes, but you are occasionally to me.*

Terry *Well, that's probably the diabetes.*

Sue *No, I think it's the other. You shout at me. [T3]*

However, at later time points it seemed that Carole, their daughter, had begun to recognise that her father might be struggling (Table 8.5):

Table 8.5: Moving towards understanding

Carole	*And I have had a conversation with him and I said, "It's not about that you're an idiot, it's the fact that part of your brain is not working. That's the way I understand it, part of your brain is not working the same as it used to. That's not your fault and it doesn't mean…it's not anything to do with your intelligence." But he's quite sensitive.*
Jenny	*He's very sensitive to that?*
Carole	*Yeah.*
Jenny	*So how does that influence your behaviour with him?*
Carole	*Well I wouldn't make a joke about his dementia and even if he made a joke about it I'd probably try and read into that does he want some reassurance that he's not an idiot or something. So*

	that's the way I tend to go about it now. Yeah you have to think about it really, not just react. [T3]

Carole recognised that he found his difficulties challenging and sought to consider how he might feel before responding. Consequently, she also tried to support her mother Sue to recognise that Terry couldn't help his difficulties and that she needed to prompt him (Table 8.6):

Table 8.6: Supporting Mum to understand

Carole	*She makes him make a cup of tea in the mornings for both of them. Because I did say to her, "You can't expect him to just do things voluntarily, if you want him to start doing things you're going to have to say to him every day probably, 'Right it's your turn to go and make the tea,' […] if you tell him I'm sure he'll start doing it." And he has started doing the tea and stuff and unloading the dishwasher and things for her. […] Yes but she still finds it very hard. She expects him to volunteer to do it but I said, "He can't you're just going to have to say, 'Get up off your bottom and do it!'" you know because she's always done everything for him and she's getting older now as well. [T3]*

However it appeared from Carole's perspective that Sue was less able to shift to understanding the impact of bvFTD, how this might influence Terry's behaviour and respond accordingly. Consequently, conflict continued to be a feature of Terry and Sue's relationship throughout the research.

In the Hugh, Burton and Lewin Families, wider family members who were out of step in their awareness, were also positioned as the problem. For example, both the Hugh and the Burton families highlighted frustrations with some relatives (Table 8.7):

Table 8.7: Positioning of family members

1 2 3 4 5 6 7 8	**Pamela**: I didn't tell my brother I was going away I thought well tough if he gets a load of phone calls that's good luck to him but he hasn't been in touch anyway. **Jonathan**: I mean he doesn't contact us, he's either in the betting shop or the club and I don't know where he'll be on the evenings now because he's not round at your mother's but I mean he is just completely in denial, he has never been a support has he? **Pamela**: No. [T1]
9 19 11 12	**Mollie**: She's seen all the pages…she's been on the website, Alzheimer's website, everything ((sighs)) I think it's just a dig because we weren't…she didn't get that attention at the time [T2] **Jenny**: I am aware that you were saying that […] your daughter […] wasn't

13	particularly understanding.
14	**Mollie**: I don't think she is, still, is she, Diane.
15	**Anthony**: Diane's very much a 'me' person. It's all 'me, me, me' and anything
16	else is totally oblivious to regardless.
17	**Mollie**: You're useful to her and if you're not useful... [T3]

In the above quotes Jonathan felt that Stan had never been supportive (lines 6-8). Jonathan's perspective appeared to be strongly held despite evidence that Stan had supported Elizabeth for around 6 years and may have experienced similar frustrations to theirs:

> *Pamela* *He was going round, I mean, he wasn't nice with her. He was going round every single day and doing a meal for her at night. But he'd shout at her, he'd be really short with her […] [T2]*

Furthermore they appeared to have made a decision to take responsibility for caregiving away from him without discussing this with him. While this decision seemed to have been motivated by a desire to ensure the best support for him and Elizabeth, it nevertheless seems to suggest that they were unable to work together to consider how best to support her. Nor were they able to consider how he might have experienced their actions. Similarly Mollie and Anthony described Diane's behaviour towards Anthony as deliberate, self-centred and lacking in understanding (lines 9-11, 15-17). Unmet expectations seemed to have been a feature of their relationship. It also appeared that they had not considered that it may be difficult for her to comprehend the changes:

> *Mollie* *Well with the family, my family, immediate family, we've managed quite well because what I did was […], go onto the Alzheimer's site and on there it gives about Anthony's dementia and I printed some off and I handed them out to them ((laughs)) and I found that…there you are read that and that'll tell you and it saved you explaining things. And that's what I did didn't I? [T1]*

As the above quote suggests, their communication surrounding Anthony's diagnosis was based on giving information sheets rather than discussion and

collaboration. It is therefore possible that Diane did not understand the complexity of the difficulties Anthony experienced with such limited information and was unable to modify her expectations accordingly.

As with the impact of positioning the person with bvFTD, a consequence of the positioning of family members as to blame seemed to result in conflict and/ or distancing in relationships. For example, Mollie described her relationship with Diane as having become problematic as a consequence of the difficulties described above. Similarly, Pamela and Jonathan indicated that communication had broken down with Stan:

> *Pamela* *My brother turned up, my brother who hasn't spoken to me and…*
>
> *Jonathan* *He just blanked me. I said, "Hello Stan how are you?" and he ((laughingly)) just ignored me, completely ignored me. [T1]*

In concluding this section it is important to recognise that Phil Horton's experience rarely featured in the coping processes described above. It is possible that his narrative does not feature strongly in this theme because their experience of bvFTD had been over a much longer period of time and Penny had already moved to a care home at the time of the research. Furthermore as their daughter did not participate in the research, we do not have her additional perspective to draw upon. Therefore his narrative largely reflected the coping processes he as an individual had needed to engage.

8.3 We're not the same anymore

In chapter seven, the challenge of *we're not the same anymore* was discussed. Changes to relationships were evident in all seven accounts, although there were differences for partners and for adult children. Many of the partners took on increased responsibility and felt the loss of many of the valued aspects of their relationship, including empathy, intimacy, mutual support, reciprocity and communication. Awareness and understanding influenced how these changes were constructed. Both adult daughters experienced changes in the relationship and also had limited understanding of the impact of bvFTD. However, their relational history influenced how they

perceived this change and it's meaning for them. A previously poor relationship gave rise to conflict and a sense of entrapment for one adult daughter. In contrast, a previously positive relationship resulted in a significant sense of loss in the other adult daughter, which in turn gave rise to difficulties in adjusting to the changes in her father.

The experiences and coping processes of these close family members seemed to be significant in impacting upon the way in which bvFTD was managed within the family as a whole. Consequently, in this chapter, this challenge is addressed before that of *managing everyday life*. The coping processes used by the five partners and two adult children to manage the changes to their relationship are now discussed.

Two parallel processes occurred, involving addressing the impact of the increased level of care required by the person with bvFTD alongside coping with the impact of the changes for themselves as individuals, as a couple and as a family. In their ways of coping, these close family members adopted three positions on the superordinate continuum, giving rise to the themes of; **accepting and adapting, fighting and distancing and being stuck.** Furthermore, they were challenged to engage in a process involving **Accepting the need for a changing I.** A number of subthemes appeared evident from analysis as follows:

Accepting and adapting

- Accepting the changes and finding new ways of being together

Fighting

- Resisting the changes, we're going to fight this together

Distancing and being stuck

- Achieving Distance
- Being stuck

Accepting the need for a changing I

- Grieving for a changing you and a changing we
- Acknowledging the need for a changing I

- Accepting the need for a changing I

Accepting and adapting

As described previously in chapter 7, the consequences of bvFTD involved an increasing level of dependence on those in closest contact with the person with dementia as the social and cognitive skills associated with living an independent life and engaging fully in relationships became challenged. Close family members were therefore required to consider ways of coping with these difficulties (Table 8.8):

Table 8.8: Acceptance and adaptation	
Jenny	*So, how do you feel having this diagnosis has affected your relationship together and your lives together?*
Anthony	*In some ways it's made the relationship stronger insofar as I'm now much more dependent on ((Mollie)) than I was before. So, we gel together nicely as a team. […]*
Mollie	*No but that's how it is now, isn't it?*
Anthony	*That's how it is. We're both reasonably good at coping, so you've got to adapt.*
Mollie	*We've adapted – that's a good word, yeah.*
Anthony	*Give and take a little on both sides – some more than others. [T1]*
Bert	*It's like having a new head on, isn't it.*
Melinda	*Yeah. That's what I said to you, I've had two of you.*
Bert	*You could have a new heart, a new liver and this that and the other but it's like having your head took off and another head put on it. You know the changes that happen.*
Melinda	*Because we can have some quite childish behaviour at times.*
Bert	*You can't do anything about it at the end of the day. It just becomes part of you, doesn't it?*
Melinda	*I think once you accept that this is part of you and once everybody else accepts, well, this is a learning experience, it's a new way. And you come to terms with that and everybody'll do it at different stages. I think that's when it becomes a lot easier. You know, I think it's just saying, well, you can't change it, it's learning to cope with it and keep a sense of humour about it all really, because we've had some laughs really, haven't we. And it's learning and to support each other not to be afraid to say to each other. And that's very important. [T2]*

As can be seen in the above quotes, Mollie and Melinda accepted the changes brought about by bvFTD and adapted in order to manage them. Furthermore, both appeared to collaborate with the person with bvFTD and

additionally in Melinda's case wider family to achieve this, as described in the previous section (p.203-7). Both partners were accepting and adapting to the changes to their relationship with the person with bvFTD. Mollie and Anthony recognised that Anthony had become more reliant on her. Similarly Melinda also reflected on how important it had become to support and work with Bert:

> *Melinda* *I think that's where we've come as a family in the last six months. It means supporting you. We've accepted more. We work with Bert. Instead of trying to change it, this is what it is and we try and work more with it, don't we. […] [T2]*

Thus Melinda had also shifted to taking greater responsibility for meeting Bert's needs, in collaboration with her family. Mollie and Melinda appeared to 'hold' the person with bvFTD through strategies designed to support their continued participation in family life and everyday activities. For example, as described previously, Mollie had found ways to enable Anthony to continue to be independent in preparing his breakfast through the purchase of a new microwave. Similarly, Melinda described how she supported Bert to continue to do the things he had previously engaged in:

> *Melinda* *((laughs)) So we are learning different ways, aren't we. And it's accepting with memory. Like, I try and involve Bert in doing what he's always done so it's like setting the table and you'll say "Set the table. Have you set the table?" Well, now, it's "Will you set the table?" and then if it doesn't happen I'd give him the placemats and the knives and forks. And that way, it's trying to find ways to stop the confrontation. And to encourage them still to do things. [T1]*

As can be seen from the above quote, for Melinda this also involved finding a balance by trying to prevent confrontation, while supporting Bert to remain engaged and active. This process of acceptance and adaptation continued throughout the research, as both partners recognised the need to adjust the strategies they used as changes occurred. In particular they both highlighted the importance of managing their expectations of what their partner could

achieve. For example, at time point one, Mollie reflected on Anthony's continued involvement to some degree in activities like sorting and responding to their mail. However by time point three, Mollie had taken over these activities because she recognised that Anthony could no longer manage:

> *Mollie* *[...] I've gone from Anthony doing it all, sorting this and taking the lead and I've had to do it now. And then you have to think, 'Well, is this right? Shall I do it? Or..?' Because I can ask Anthony and he'll say 'Oh yes. We'll go and do it.' or whatever. Even if it's wrong. He'll tend to just agree. [T3]*

While both Mollie and Melinda described active processes to collaborate and engage with the person with bvFTD, it is nevertheless apparent from these quotes that they were taking responsibility for their partner. Such responsibility involved a significant shift from their previous relationship, where the work of relational and family life appeared to be shared between them. Therefore as described previously, Mollie likened this to the care she would offer a child:

> *Mollie* *Anthony's as good a gold but he's always looking now for, "Shall I do this? Shall I do that?" or it's like, as I say it's like a child looking for approval, it's strange, whereas he used to be the one who would take control if you know what I mean but he can no longer do that. [T2]*

Phil Horton's narrative also highlighted that he had needed to take responsibility for his wife Penny's wellbeing and that this had begun before diagnosis and continued throughout her experience of dementia. For example, he described cuddling her to make her feel secure:

> *Phil* *But it would be a case of me holding her rather than her responding to me if you know what I'm saying. Trying to make her feel wanted, trying to make her feel secure, basically. [T1]*

He also appeared to focus on acceptance and adaptation although his experience appeared to be significantly different from Mollie and Melinda for

reasons described previously. Consequently he felt that he had needed to manage on his own and seemed to describe a process of adapting and compensating as changes occurred:

> *Phil* *I just used to compensate for the situation, […] so never really harmed our relationship. I mean, there have been occasions when things have happened and you think "Well, what was that for?" and "Why did that happen?" but then you readapt. For me marriage was for life and not just for an occasional few years. So that was my way of life and it was just a case of adapting to the changing circumstances really. [T1]*

While placing her in a care home had been a necessary but difficult decision for Phil, he continued to adjust and adapt in order to support Penny. At time point two and three, he had sought to adjust to this new situation by collaborating and communicating with the staff in the care home. This involved working together with the staff to make her life better (Table 8.9):

Table 8.9: Collaborating with staff

Jenny	*You mentioned last time she'd lost a lot of weight.*
Phil	*Yeah but she's down to five and a half stone and what they've decided to do […] which I totally agree with, well it was my suggestion, somebody that weighs five and a half stone surely doesn't need the same level of medication that somebody that was 12 stone needs, so they've reviewed the medication and they've taken her off, she's not been on an antipsychotic for about six months which is good. […] So they've gradually weaned her off that and she's not on Sertraline anymore. And I think going forward I'll gradually look at all the [medication] because she was on an absolute massive amount of medication at one stage. [T3]*

Thus Phil continued to take responsibility for Penny and for her needs and had adapted to the changing circumstances by working with staff as well as visiting and supervising regularly.

Fighting

Consistent with her view of herself as a capable and strong person who could overcome challenges (c.f. chapter 6); Kate Perrin chose a different route to

managing the experience of bvFTD. Although she understood that it was progressive, she decided to fight the changes associated with bvFTD for as long as possible. Fighting involved using the sort of processes she would implement with children that had difficulties with processing and sense making as described below (Table 8.10):

Table 8.10: resisting the change, we're going to fight this together	
Jenny	*How did you arrive at the decision to take that route […]*
Alistair	*I don't know.*
Kate	*You didn't.*
Alistair	*I didn't, no, I didn't. yes, you had a friend that had a brain injury and information that he was giving you from that sort of put two and two together and... […]*
Kate	*Because of the SENCo work I do and the working with little people, what I did was took everything I knew from there and converted it to making it work. What would I have done for a child that couldn't process? Well I would have put in a visual timetable, I would have done this... So that's all we've done at home, is make everything visual. So all the skills and the things that I would have done in a classroom for a child that was struggling is what we've tried to put into the house. It isn't rocket science to do it, it just needed thinking through in the first place. And I think I didn't give you a choice, I think the route we took was... I was so adamant...*
Alistair	*That it wasn't going to get the better of us.*
Kate	*Yes. And if we stayed together and we stayed strong together we could beat anything.*
Alistair	*Yes.*
Kate	*And we ca... we are beating it, we are winning, because [psychiatrist] said that...*
Alistair	*Yes.*
Kate	*I'm going to phrase this badly but I'll do it anyway, the decline in your capabilities hasn't been as great as she would have anticipated. So we are holding it off, it is hard work but we are doing it.*
Alistair	*And it's easy to slip and let it go. [T1]*
Jenny	*How do you manage the change in your relationship?*

Kate	*How do I manage it?*
Jenny	*How do you cope with it?*
Kate	*Just accept it. There's nothing else you can do. There's no point in being angry, I've been angry, I've done that. There's no point in being upset. There's no point in changing it, it is what it is. [tone tremulous] [T3]*

As can be seen in the quote above, while Alistair appeared to agree with the strategy, both acknowledged that it was Kate who was the driving force behind the decision to fight. Indeed Alistair seemed to acquiesce to her decision to respond in this way. Kate also sought to achieve this in collaboration with her family as can be seen from their narratives (Table 8.2). In the first quote at time point one; it appeared that their interactions with the psychiatrist confirmed for Kate that they were doing the right thing. Kate's tone of voice during the times when she was discussing this approach appeared strong and clear.

Her commitment to this strategy continued into the third time point and as described previously, she adapted and adjusted her strategies as Alistair's needs changed. However when talking about how she felt about the changes, there was a marked difference, with her tone reflecting anger, sadness and loss. Therefore while by time point three, Kate referred to acceptance as the only way she could cope with the changes, it appeared that this came with a considerable cost as she had to accept that the changes were occurring no matter how hard she fought them.

Distancing and being stuck; achieving distance

Consistent with the discussion of resisting and blaming explored in awareness of the changes (p.208-12), one partner and two adult daughters and their partners struggled to move to a position of understanding the impact of bvFTD. Consequently, the person with bvFTD appeared to be positioned as the problem and on occasions, their behaviour seemed to be interpreted as deliberate. In this context, as described previously, the two adult daughters achieved some distance from the person with bvFTD as a coping process. A core part of distancing involved becoming care managers and limiting the amount of direct care they provided. While this strategy had

benefits, it also appeared to be at times an added cause of stress. For example, Sarah Lewin described a battle to get the help they needed at the first time point, although once this was in place she valued the support she received, including regular carers and respite breaks (Table 8.11):

Table 8.11: Feeling supported	
Sarah	*Yeah and what's the point in getting stressed. The respite has helped so much. It just gives us so much of a break. We didn't realise it's not just Dad it's everything, you know, the carers coming in, you know, they're helping now but they're invading our privacy. Now I don't mind, you know, they've just come in now they're going to be helping me out but in the morning they're here at half six, they wake the dogs up, they wake the kids up, we don't get a lie in. They're then in at quarter past, half past nine, well I don't like them being out in the dark so I say if you've finished come here I don't want you sitting in the lay-by it's dangerous. So they walk in. Now that's fine they can chat to Dad but again it's they come in and it's invasion of privacy, they're in my home, I can't come down in my dressing gown and get a drink and whatever. So it's just like argh!*
Alex	*I find that the hardest I think.*
Sarah	*Yeah but we have now…*
Alex	*The invasion of privacy really. [T2]*

However, she and Alex point to the difficulties associated with the invasion of their privacy that came with having carers in their home. Similarly Pamela described the many phone calls and resulting stress she experienced because the care agency did not appear to recognise the limits within which they had to work. At times she suggested that they made the situation worse (Table 8.12):

Table 8.12: It's a double edged sword	
Pamela	*We did have an issue with them because they're supposed to actually buy her day to day stuff like for her lunches. I do all the ordering for frozen meals and all they have to do is to buy something like salad and bread and milk and toilet rolls and cleaning stuff and there was an issue about how much money we were giving to them and I had a meeting with them and I said, "Is that amount okay?" and they said yes, the next week they email me and she says, "We're out of money." So I emailed them back and just said, "Well how come last week you said that you had sufficient money and now you're telling me you've run out? I've had no receipts, I don't know what the money's been spent on so*

	what have you used it for?" So the comment back was, "It's been mostly on cleaning material and it would be in Elizabeth's best interest if you purchased it." So I started…
Jonathan	*Over and above the budget that's given to them.*
Pamela	*So as far as I was concerned they've got a budget and they should stick to it. If you give them say £120 and it's four weeks then they've got £30 a week to spend and we have to manage our budgets don't we with food and what have you so why can't they manage a budget as such. [T1]*

Therefore achieving a distance through care managing was an important coping process to manage the difficulties they experienced. However it seemed to be only partially successful in achieving the balance these adult daughters needed in their level of engagement with the person with bvFTD.

Distancing and being stuck; Being stuck

As described previously, Sue Stuart appeared to struggle to understand the difficulties associated with bvFTD. Furthermore, throughout the research she reflected on the loss of the qualities she had valued in her marital relationship such as being cared for and supporting each other:

Sue *There's no loving, we're more like brother and sister.[T3]*

It seemed that Sue also struggled to find a way to address the challenges brought by bvFTD for their relationship and their lives together. She initially appeared to minimise Terry's feelings about the difficulties he was experiencing:

Terry *But there's a stigma about it isn't there without doubt, you know and people say, "You've got dementia, oh!" you know, they won't say it to your face, it's there. It is there.*

Sue *I think you're imagining it. [T1]*

However, later in the research Sue described accepting their situation and appeared to be trying to find ways of managing the challenges including seeking ways to enable Terry to remain active. She also described walking away when conflict between them arose and engaging in activities they both enjoyed such as going on holiday. However she often felt that these attempts were unsuccessful. For example, she described the problems she

experienced with asking Terry to do household activities (table 7.4) and those associated with going away on holiday with Terry (Table 8.13):

Table 8.13 Being Stuck	
Sue	*Well, it's just accepting the situation and making the best of the situation. That's what it's about. I just get upset inside the fact that I have to do everything, because I sometimes think "Oh, it'd be nice to be waited on."*
Terry	*This is why we have our holiday, so you can be waited on.*
Sue	*Yes, but I'm not waited on when we go all-inclusive. You go off and get your meals and leave me to struggle getting mine.*
Terry	*Oh, I'm the villain again.*
Sue	*Yeah, I'm not really happy with having to keep going and getting my own food in front of...*
Terry	*But they don't do that anymore. You don't get a service*
Sue	*I know, but he's insistent that we do all-inclusive so I have to go along with what he says. What he doesn't understand is I'm unsteady and I have to keep trying to get these tongs and all sorts of other things. Ooh, I just think that I could pick it up with my fingers, it'd be so much easier.*
Terry	*I do bring you coffee. And your drinks.*
Sue	*Yeah, he goes and gets the drinks. Because I couldn't do that.*
Terry	*I can't choose your meal for you.*
Sue	*No. I know that, Terry.*
Terry	*You've got your own choice.*
Sue	*But that's what it's about. You're saying I'm being waited on, but I'm not really, am I? [T2]*

It appeared that Sue experienced resentment and sadness that Terry could not do these activities for her and was no longer able to support her in the way that she felt she needed. Thus it is possible that Sue experienced feelings of being stuck in this situation. It certainly seemed that Sue had become resigned to life continuing in the same vein and having little control over it:

Sue *I just think it could be a lot worse. And I've just got to make the best of the situation. I don't dwell on it. I mean, you've got to cope, you've got to live together, haven't you. [T2]*

It seemed that Sue may not have had the emotional and cognitive understanding needed to identify and implement alternative coping processes. Although she had experienced support initially from her local services, it did not appear to have continued beyond initial post diagnostic interventions. Thus a possible source of support and assistance to develop these strategies was not accessed and/or was not available.

Accepting the need for a changing I

Alongside managing the increased responsibility for the person with bvFTD, it seemed that these close family members engaged in a parallel process of managing the impact of this change on themselves as individuals. Changes in emotional and cognitive sophistication resulted in an early shift in the relationship and therefore also in everyday relational work. Although Pamela Hugh did not express a sense of loss with the changes in her mother, she nevertheless acknowledged changes in relationships as a consequence of her mother's illness. The realisation of these changes resulted in the expression of grief and loss for these close family members (Table 8.14):

Table 8.14: Grieving for a changing you and a changing we	
Phil	*You just do the best you can. If you really care for somebody you will do the best you can for as long as you can. I mean the last thing I wanted is for her to be seriously ill and the very last thing I wanted is for her to be out of my life. I just want to try and do the best I can for her [T1]*
Jenny	*I guess that one of the things that I was aware of was when we very first met you talked a lot about that your plans had been, once you retired, … to go off all over the place.*
Mollie	*Do you know what, I think that hit me more than anything. Everything just stopped. […] [T3]*
Melinda	*Yeah and it is very difficult losing the person that you loved and trying to learn to love the other person. Very, very difficult. And one thing you can't do is compare. I'm not going to get that Bert back. So it's learning to love this one. And acknowledging to yourself that that is not going to be easy. But you get there. [T2]*
Kate	*And I suppose if the one thing that I've learnt in all of this is what will be will be and I mean years ago for example I would have*

		yelled and ranted and raved, I don't even do that now do I, I just […] Because there's nothing you can do. I mean I don't like it. I don't like the fact that the one person that was always by my side and always so strong where I was wussying and airy fairying around isn't there in the same way. I mean he's physically still there but it's not the same is it? […] and I suppose that's the mummy tiger because I'm not going to allow it to happen but how I manage it that's all you can do, I can't manage it, what am I going to do? [T3]
	Jenny	*The last time when we were talking you were saying you were going to have a christening.*
	Sarah	*Yes we've had that. He stayed here didn't he?*
	Alex	*Yeah he didn't come in the end.*
	Sarah	*No we asked him, asked him and asked him. We said that we would pay for a taxi down for it to wait, because it was the same church that we got married in so that wouldn't have been, you know, it was somewhere that he would…it was the family church, he knows it and no. Too much, couldn't…yeah.[T3]*
	Sue	*But that's one of the hardest things I think, that side. You know he doesn't, he'll never hold my hand, I have to hold his arm because I'm not very steady now when we are walking in [village]. But I feel as if he keeps on doing this it's as if he doesn't want to do that you know what I mean? I said to [nurse], ten years ago, or 15, when we'd be on holiday and everything we'd be holding hands walking along but now it's absolutely nothing. [T1]*
	Pamela	*And I'm just amazed at how it's affected our family. You can't believe that you know […] we're not even talking to each other.*
	Jenny	*And is that different from before?*
	Pamela	*Yeah. Initially, when she was first ill we used to talk frequently, because I'd be phoning up and saying "Ooh, she's done this, that and the other!", or whatever. Or he'd be saying, well, he was the one who first tipped us off that there was something wrong. […] So initially, we were talking. But to now be at the stage where we won't even speak to each other unless there's something specific to say. [T2]*

Close family members experienced grief relating to the loss of; companionship and hope for the future, expectations of a future together, a life partner, intimacy and togetherness, closeness and family cohesion. Furthermore, some close family members identified personal costs associated with the changes in the person with bvFTD and their caregiving role, particularly when trying to manage this alongside the other pressures experienced in their lives (Table 8.15):

Table 8.15: Personal Costs	
Phil	*So everything revolves around that and that colours the way I feel day to day. I find that I can't concentrate like I find it difficult to sit down and as I say I'm very interested still in the music but I'm not able to sit down and concentrate and practice and do things that I ought to be doing. [T2]*
Kate	*That's why I got so frightened in January when I really thought I'd got dementia, I really believed I'd got it, I sat at a meeting at work and there were all these people round and I knew I knew all of them, I knew I knew who they all worked for but do you know I couldn't have told you and I got frightened and I thought well I've got alcohol induced dementia obviously because if I'm going to go anywhere it's going to be through alcohol [T3]*
Pamela	*It's just so awful though because I mean like I wasn't very well a few weeks ago was I and my blood pressure was absolutely through the roof and when you keep having the phone calls all of the time you just think, I just can't do this any longer. [T3]*
Jenny	*One of the things I was aware of, Mollie, […] you yourself had started to feel quite pressured and stressed. And I wonder if you could tell me a bit about what was that like for you?*
Mollie	*Oh yes. I think it's just the build-up, from January onwards, because obviously family were at the hospital. [my son was ill]. They didn't know if he was going to pull out of it, because they kept saying to me "Do you realise how seriously ill your son is?" And I thought "Well, I've taken him to the doctors' every time." So and I thought "Well, I can't do any more." So we had all that time with Pete and then got him settled. And then we went away on holiday and it was a disaster. Because I was trying to look after two other people who just said they've got this wrong and that wrong and I thought "Oh, I don't need this." And I was trying to please them because I wanted them to enjoy themselves. There was absolutely nothing I could do to please them and in the end I said to them both "I'm here to look after Anthony, not you two. I can't look after three of you." So we came back and it didn't feel like a holiday. […] So I think with the build-up of everything I felt I couldn't cope. I wasn't coping. [T3]*
Melinda	*[sighs] It is frustrating for you and I don't think it's helped because normally I'm very proactive and I will push it and see things through but emotionally I was drained. [T2]*

Costs included physical ill-health, stress, impairments in cognitive function and becoming emotionally exhausted. Furthermore, some close family members worried about how possible changes in their own health might impact upon their ability to care for the person with dementia. Realisation of these changes and their impact resulted in a challenge for these close family members to acknowledge the need to grieve and find ways of coping.

Close family members were variable in the extent to which they were able to address this. For example, Phil suggested that he had become a more emotional person as a consequence of his experience (Table 8.16):

Table 8.16: Becoming more emotional

Jenny	*How's that been for you?*
Phil	*I've always been the backstop within the family. If there's been a family crisis like when my father died, that was 1972, or when my mother died, or when my brother and sister died I've always been there for the others. And always remained strong throughout. But recently, as Penny has deteriorated significantly, I've had trouble holding it together. And I've got emotionally upset. On a few occasions (quiet, pause). I make no bones about it, I am a pretty emotional person, sentimental old fool you could say and I have been affected by it, yeah. Absolutely. I've got the specialist nurse, […] who comes and sees me, probably every six weeks. But ... apart from that you're on your own really and I haven't got loads of family as you can see from that. I've got some very good friends and I just tend to be able to rationalise things out. [friend] is still a very good sounding board. But yeah, I have become significantly affected over the last few months. From time to time. I was very upset on Tuesday when I realised that, she didn't ... ... recognise, when I went anywhere near her she was screaming just as much as she was with anybody else. That was pretty significant really […] [T1]*

In doing so, he recognised that he needed others help and identified accessing psychological support from a specialist nurse and from a few close friends. Similarly Mollie, Pamela and Melinda described that they had valued the psychological support they had received, also from specialist nursing:

> *Melinda and then [specialist nurse] was absolutely a godsend bless her because I was able to go and unload, which I'd never done with anybody. And that, I think, kept me sane and helped me cope. [T2]*

In Melinda's case this support assisted her to address the changes in her relationship with Bert as well as understanding how to support him. However,

three of these four family members described circumstances in which they were no longer able to access the psychological support that they had received and all were concerned about how this would impact upon them going forward. For example, Mollie indicated that the specialist nurse she had received support from would be leaving and not replaced and appeared to be worried about how she would cope without this, something she mentioned after the recording had finished (T3 reflective notes).

> *JLF* *Although she was concerned about the future as the specialist nurse was leaving and what this might mean for her. [field notes T3]*

All four described friendships, peer support and family as being additional and important sources of help to them as individuals. For example, in table 8.16, Phil identified friendships that he relied on to express how he felt. Similarly Mollie described the value of friendships they had made with others who were in a similar position at the Alz Café:

> *Mollie* *And if you're having a bad day, or something's not right, get on the phone and somebody'll listen to you at the other end. And that's how we do it, go on, isn't it. But I think it's because we've got a good circle of friends who are in a very similar position.[T3]*

Having the support from others who listened and understood seemed to be a particularly important way of coping with their feelings of loss.

The three other close family members who participated did not appear to address their needs in this way. Sarah appeared often to talk about her loss in terms of how her father had changed or what he did rather than expressing how she had experienced this change (c.f. table 8.14). Furthermore she did not appear to have accessed support to consider how she experienced the changes.

Sue and Kate seemed to be more expressive of the challenges they faced. Indeed both described how their partner had changed (c.f. table 8.14). Nevertheless, Sue seemed not to see professional support as an answer to this and had not utilised the professional support that was available to her.

For example, Carole mentioned that Sue had seen a specialist nurse on a few occasions:

> *Jenny* *Is that [specialist nurse]?*
> *Carole* *Yeah I think it is yeah.*
> *Jenny* *Okay.*
> *Carole* *Mum seems to find her visits very helpful, just getting out. [T1]*

However Sue did not mention this support in her interviews and by time point two, the specialist nurse was no longer involved. Sue may have struggled to address feelings of grief, as she also appeared to have unresolved grief from the death of her father ten years previously. Furthermore Sue appeared to feel quite isolated, suggesting that they had struggled to make friends since their move:

> *Sue* *[The neighbours] are always going on holidays or they're going to somewhere with the children somewhere, they go off for weeks on end. We call them the invisible neighbours sometimes. […] So it is very quiet. But what we try to do is go to [village], we'll have a walk round and by the river. [T1]*

This isolation may have further added to her difficulty with finding sources of support. However by time point three, they had established new friendships, although it is not clear whether these friendships were such that she would have been able to confide in them, if indeed this is something she would have sought.

Kate also did not appear initially to have sought forms of support to address her grief. She described feeling that she couldn't share with her family or with professionals. For example, she suggested that it would be inappropriate to share her feelings with a professional because she was a similar age to her daughters:

> *Kate* *But it'd be like trying to talk to one of my daughters. There's things I can't talk about to them. And I think that's hard. […] She's lovely and so it's not a criticism of her. Who else in their right mind would want her job, to be honest? ((laughs))*

Must be really tricky. Because you're constantly dealing with the negatives of things. That must be tricky. [T2]

However, she might also have been struggling to acknowledge and express her own feelings at a time when she was heavily invested in trying to prevent further deterioration through the strategy of 'fighting it' referred to earlier. Later in the research, it appeared that Kate was becoming more open to addressing her grief. She described relying more and more on her family for support, in particular talking with her mother:

Kate *I can always pick up the phone and talk to my mum, she's always up for a chat, in fact that's why it took me so long to do the ironing last night because I ended up being on the phone nearly 45 minutes with my mother when you went out […]. [T3]*

Rena *I'm her safety valve, I think.[T3]*

As the above suggests, Rena perceived that she had become Kate's confidante. Kate also appeared to have benefited from peer support and in particular described her contact with two local groups:

Kate *But it is hard and it is isolating. The [young onset carers group] are brilliant. That's lovely. But because I work, I can't always get there and they're talking about bringing [the young onset] Al's Cafe earlier so that more people can attend. Well that will just take me out completely because I struggle getting there some nights for the time it is now. [T2]*

However, as indicated above, this was not without difficulties as Kate was in full time employment at the time of the research so consequently it was not always possible for her to attend these meetings.

In addition to accessing professional and peer support and the support of friends, close family members described additional ways of coping with the feelings of loss. These included making broader choices about what they could commit to in their lives:

Mollie *And I went and I thought "Okay." and I had to walk away. I said "Pete, I've got to go." And I haven't been there since*

with him, have I. I walked away. I couldn't cope anymore. But I'm finding it a lot better now. I just had to walk away. It was either that or I wouldn't be able to look after Anthony. You can only cope with so much. And I was thinking... I was snapping with my friends and I didn't want to go to these meetings. You isolate yourself. You don't want to... But now we're getting out again, aren't we. [T3]

Mollie suggested that she had taken on too much in trying to care for her son as well as Anthony. She recognised that she couldn't do it all and had to make some decisions about her priorities. Both Pamela and Sarah had made a similar decision by engaging care agencies to support their parents. Kate also referred to having to give up some of the activities she had previously enjoyed because of Alistair's increasing needs. Phil also had to make a significant decision in placing his wife in long-term care due to the level of support she required:

Phil *I'd still prefer her to be here but I just don't think I'd be able to cope even with 24 hour assistance, you know, it's just…I never know from one minute to the next how she's going to be and that's really where we are. [T2]*

However, as referred to in Phil's quote, it seemed that these decisions were often not straightforward. It appeared that the decision Phil had made created dissonance because he would prefer Penny to be at home.

Caring for oneself also appeared to be an important strategy. Mollie and Sarah referred to attending carers' courses as a way of learning how to manage and therefore alleviate their stress:

Sarah *It does, it depends what sort of mood we're in. I think we've learnt. I was always getting really agitated and argued back with him and since I've been on the carers' courses, I've learnt that there's no point in arguing back because you won't win. [T1]*

Similarly, having time for themselves was mentioned as an important aspect of self-care:

Sue *But it gives me a little bit of a break as well. I mean, the first week was lovely, because I went out with my daughters to the centre and I really enjoyed that and we had something to eat. And it was a nice little day because we're never really apart, you see. [T2]*

Time out was achieved in a range of ways, including walking away when situations became stressful, taking time out at the gym, sleeping in a separate room and communicating with friends, including the use of social media.

8.4 Managing everyday life

In chapter 7, the challenge of managing everyday life was considered. All seven participating families suggested that bvFTD had a wide ranging impact on wellbeing, relationships, activities of daily living and other aspects of family life.

This challenge was influenced by awareness of family members and the availability of supportive professionals. Furthermore, knowledge of similar difficulties and contact with knowledgeable others such as peers also appeared to influence how families responded to the impact of bvFTD on everyday life.

The coping processes that these seven families used to manage this challenge are now discussed. It appeared that these coping processes were underpinned by core components of family functioning including collaboration, communication, the ability to address conflict and cohesiveness. These have already been discussed in the first two sections in this chapter. Furthermore, as described in the previous section (p.212-31), the coping processes of the family member most closely involved with the person with bvFTD appeared to have a significant influence on wider family coping responses. In their ways of coping, close family members adopted three positions on the superordinate continuum, giving rise to the themes of:

- **Enabling and facilitating,**
- **Distancing, managing and controlling,**
- **Avoiding and reacting**.

Each of these themes is now addressed in relation to coping with the impact on relationships and coping with the impact on everyday activities of living and self-care.

Managing the impact on relationships

Enabling and Facilitating:

In some families, this impact of bvFTD on relationships was addressed through the cohesive, collaborative and reflective nature of the families, which included the person with bvFTD and wider family members. As described in the previous two sections (**we're not the same anymore** and **awareness and understanding of the changes**) the Perrin and Morris families worked together to understand the changes, develop and implement coping processes. The partners of the person with bvFTD appeared to be central to facilitating this process. Melinda Morris suggested that it was important for her to be proactive and support her family emotionally (Table 8.17):

Table 8.17: Engaging with and supporting each other as a family	
Melinda	*But I would say as the mother, or whoever it's going to be in that family, they need to be proactive. In that you've got to get an inner strength and come over so that they're not afraid to say how they're really feeling. And like with Adam, I was quite able to say to him "I'm really angry and annoyed that this has happened." And that encouraged them to come back then and say "Angry? I want to thump the door!" And it's encouraging that, because you can't just think, because it's not like cancer, it changes your personality. And reminding each other when things go wrong and you do forget things. Because you can have a really good period where things are really good and then even during a conversation you can be really good at the table and then completely forget. And it's encouraging each other, "Well this is part of it." Just move on. Don't dwell on it. And that helps everybody then. [T2]*
Bert *Melinda* *Bert* *Melinda* *Bert* *Melinda*	*Idris pops in through the week ...* *And it's just support, he takes you fishing. We see these every day.* *Sam does.* *Because Amy's Polish and her thing about the family is different and she's a little star, an absolute star.* *I mean Adam lives in [village], but he comes more often now than when we were in [previous area].* *Yeah, but we try not to ... if I need some support, or if I feel you need the support of someone different to me, I tend not to go, he would be my last*

	choice. I tend to go to Idris and Sam and then Kelly and Margaret and we do it that way, don't we?
Bert	*Mm.*
Melinda	*And each one of them offers Bert something different in their approach.*
Bert	*I mean Adam takes me out for a half day, a day.*
Melinda	*He's good that way, you go and do nice things together, don't you?*
Bert	*Mm. [T2]*
Melinda	*Because even though you're sharing this journey, Jenny, you don't want them, at this stage anyway, to experience every part of this behaviour, because it's hard for them. I'm their mum and they've not been used to the way Bert can be towards me sometimes. So it's recognising that and as long as I feel able that day to do that, is to accept that. [T2]*

In being proactive, Melinda appeared to address the emotional wellbeing of her children in order to support their adaptation to the changes Bert was experiencing. Furthermore, this coping process appeared to enable the whole family to move to a position of supporting Bert to manage everyday life, which in turn also supported Melinda. In achieving this collaboration, Melinda described needing to be mindful of the differences in adaptation of each of her children as this influenced how much she would ask of them. Furthermore, it appeared that she also sought to protect them from knowing everything about Bert's behaviour as she felt this would be too much for them.

While such protection wasn't always possible, open communication of emotions enabled them to address the impact of his behaviour as described in chapter 7 (Table 7.10) and here (Table 8.18):

Table 8.18: Open communication of emotions

Melinda: We try and after each outburst, if there's an outburst with him, I will ring whoever it is and talk them through it, because it's very hard when you've had this very loving dad, who has always been very calm and will talk things through, to one that will just go like that ((snaps fingers)) […] [T1]

Melinda described needing to find an inner strength in order to achieve this and in this respect appeared to feel responsible for the wellbeing of the whole family.

In the Perrin family, as can be seen in the previous section, (p.217-9) Kate was instrumental in developing the coping process that they used to support Alistair and engaged their family in enabling this approach to be implemented. Thus the family seemed to be united in supporting Alistair. This collaboration appeared to continue into time point three (Table 8.19):

Table 8.19: Perrin, engaging with wider family	
Rena	*And if he wants to come out with us he does and if they back out at the last minute, okay, that's fine, or whatever. We don't put the same rules that you would put on I suppose if it was anybody else. Because we want him to be as comfortable as he can. And Dave goes there most weekends, Dave is there. And what Dave says is 'Do you need me this weekend?' and if they say no, they don't, that's fine and if they say 'Yes please.', then he goes. [T3]*

While this level of collaboration with wider family did not appear in the remaining five families, there was evidence of communication and co-operation in some. For example, Sarah Lewin described some of their family as helping by visiting regularly and Carole Stuart described her involvement in supporting her mother. This appeared to be limited to visits or telephone calls but it seemed to be supportive of the closest family member and/ or to the person with bvFTD (Table 8.20):

Table 8.20: Engaging with wider family, communication and co-operation	
Sarah	*We have such support from Alex's parents and his brother and well yeah we haven't seen [sister in law] for a long time, […], but his brother will come and sit with my Dad for an hour…*
Alex	*Yeah just chatting.*
Sarah	*Just chatting. And they'll chat about anything. Well they haven't really got anything in common but [Alex's brother] will come and…*
Alex	*He makes the effort.*
Sarah	*He does make the effort and it's great and Aileen and Tony, [Alex's] mother and father, come and every time they come and sit with him, they don't come and sit with us, they come and sit with Dad and go through and they'll really put the world to rights and have sensible conversations.*
Jenny	*So in many respects it's really quite different in terms of the people who do come in comparison to your…*
Sarah	*Yeah. And even, well my Nan comes over to see the kids which is my mother's mother. Now and my Mum comes down and she has, you know, spends time with him. So the ones that you wouldn't*

have thought would… [T2]

Consequently while some family were not supportive, Sarah and Alex appeared to feel that others were and that they all benefitted from this. Similarly Mollie Burton and Phil Horton reflected on the supportive nature of their contact with their siblings:

Jenny *Yeah. So in terms of who you have, the relationships that are important to you now is that family or are there others who are important to you?*

Phil *I've got some very good friends who I see more so than I see the family. I see Penny's brother probably once or twice a week. I see my brother every other week probably and we speak on the phone daily. They'll phone me. My own brother will phone daily to find out how things are with Penny. And her brother I'll phone him when I've been to see her and tell him how she is. So we keep in touch by phone quite significantly but I have got some very good friends who are supportive [T2]*

As can be seen above, Phil reflected on supportive friendships too, as did Mollie (c.f. p.227). However, it did not appear that the emotional experience and needs of the wider family in regard to the impact of bvFTD were explicitly addressed.

Distancing, Managing and Controlling:

In five of the families, as has been discussed previously in **awareness and understanding of the changes** (p.208-12), working together to address the impact of bvFTD and moderate its impact on relationships appeared to be less in evidence. In some of these families, members who were out of step with close family members were positioned as the problem. This positioning appeared to result in these family members being blamed for their lack of understanding. Additionally it seemed that close family members sought to achieve a distance from them and/ or experienced conflict in their relationships with them.

Furthermore, as discussed previously, it appeared that even where relationships continued, they lacked cohesion and collaboration. For example, Jane Burton's involvement in her family appeared to be about keeping in touch with her father (p.207). Jane's narrative appeared to suggest that she recognised there was a risk of an increasing distance in her relationship with Anthony. She described that she had made considerable efforts to keep in contact with her father and Mollie since his diagnosis. For example, she referred to having to visit more frequently because Anthony was no longer able to communicate via telephone, something they had done previously:

> *Jane* *I think there are certain aspects of it that may have changed because of the diagnosis. For example, the phone. He won't speak over the phone at all now whereas before I could keep in touch with him by calling him on the phone and talking to him. And now he won't do that at all so it's a case of I have to go over and see him. And obviously now that he doesn't drive because of the dementia as well he can't come over to see me either. [T1]*

Consequently, even though Anthony and Mollie appeared to feel that she was the one person who could be relied upon to visit:

> *Anthony* *Because Jane popped in last night didn't she?*
> *Mollie* *She pops in on her way from work doesn't she in the hospital. She works at the hospital and she's good. She's quite thoughtful Jane.*
> *Anthony* *Yeah she's the thoughtful one of the two. [T2]*

Jane seemed to be concerned about the risk of increasing distance from her father.

In other families it appeared that a lack of shared understanding and collaboration resulted in a decision to allow relationships that were no longer meaningful to drift apart:

Sarah *It's up to them it's their loss, you know, I know what he's got, […] he's been properly assessed, if they don't want to believe it and if they don't want to help out or come and visit then that's their loss of…they could still get a lot of pleasure from their brother at this stage of his dementia rather than, you know…*

Alex *There's no point coming round when he's drifted any further, if he drifts out further. […] But their situations I find extremely odd really with the sisters because I think they should be around a lot more than they ever turn up. [T2]*

Consequently while Sarah and Alex felt that Ray's sisters should be more involved, they appeared to accept that this wouldn't happen.

Avoiding and Reacting

Similarly, distancing also appeared to occur in the Stuart and Horton family although it appeared to have been a way of coping previously (c.f. chapter 6).

In spite of the pre-existing relationship difficulties, Carole Stuart described establishing and maintaining a greater level of contact with her mother since her father's diagnosis. Her mother Sue confirmed that she had regular contact with Carole and involved her in their lives (c.f. chapter 6). Nevertheless when discussing the impact of bvFTD at time point one, neither Sue nor Terry appeared to feel that it had impacted upon their children:

Jenny *How do you think having this diagnosis has affected your relationship with your children?*

Terry *We don't hardly see them anyway but it ain't*

Sue *I don't think at this stage, Jenny, that it's made...*

Terry *Any impact.*

Sue *I mean both of them do not seem to be surprised of the diagnosis. To me it's like they've always thought something ((laughingly)) not right with your dad. It's awful to say but that's what I think. [T1]*

As described by Carole in chapter 6, it appeared that there was a lack of communication within this family about their experiences and needs.

Consequently, it seemed that this greater level of contact appeared to create further challenges in their relationships. At the third time point, Carole indicated that she had limited her contact with her parents because her mother had not been honest with her and had let her down at Christmas when she had made an effort to look after them:

> *Carole* *She was supposed to be staying and then they made lies up to go. And I didn't appreciate that because I had to clean the house…because mum's spotless, I'd cleaned the house and working full time and trying to do everything it was a lot, I was absolutely exhausted and I was cooking dinner for them on Christmas day […]. So we could have had such a more laid back Christmas if it had just been, you know, if I knew they weren't staying over whereas I had to change all the beds and get it all …clean all the skirting boards because I knew she'd be looking at it, so that really annoyed me at Christmas, really annoyed me that I'd put so much effort into it and she knows how busy I am and she couldn't tell me the truth. And we did have words about it but not quite out in the open because she just gets too upset about things. So yeah. So it's knocked things about because we were…because I was taking her to the hospital and stuff before Christmas, we were getting quite a lot closer really but I've sort of stepped back again. [T3]*

Carole suggested that the reasons for less contact were related to the lack of honesty within the relationship. She further suggested that it was difficult to be honest with her mother about the reasons for her distance, because of her emotional fragility. This seemed to result in a repeating pattern within this family, in which relationship challenges were denied or avoided, consequently distancing occurred.

Finally, Phil Horton appeared to describe a historical degree of distance with their daughter after she had left home (c.f. Chapter 6). He also seemed to feel that his daughter found it difficult to cope with her mother:

Phil *On one occasion my daughter came to visit and my wife actually hit my daughter. Big time. Three or four times during a two or three hour period. […]*

Jenny *How has your daughter been affected by...?*

Phil *Well, because she's got the two children and she lives so far away she's not been able to visit very often, but she's found it difficult to cope with. […] I just think because it's her mother she can't cope with the situation. I have been of the opinion that she's been in denial really. But I don't necessarily think that's the right word to use. She hasn't really visited her mother as often as she probably needed to, to keep the contact going. That is difficult sometimes for me to cope with. [T1]*

While it appeared that some contact was maintained through occasional visits, their daughter might also have maintained a distance as a consequence of her mother's behaviour. Although it appeared that Phil struggled with this at time point one, by time point two he appeared to have accepted the situation as it was:

Phil *We still get on. We're okay. I mean initially when her mother was really ill and particularly when she went into the hospital I guess I probably expected my daughter to come and see her a bit more often than she did but over time you just learn to live with the circumstances really and it doesn't in any way bother me any more now. [T2]*

It did not appear however, that Phil had considered how his daughter might have felt about the changes in her mother although it is not clear from the interviews why this might be the case.

Managing the impact on everyday activities of living and self-care

Enabling and Facilitating: *Scaffolding*

This section addresses the coping processes used to manage everyday activities of living and self-care. Two families and one couple (Morris, Perrin and Burton) utilised coping processes that supported the person with bvFTD

through planning and preparation, anticipating difficulties, providing routine, structure, support and prompting and providing safety when this was required. As can be seen in the section in this chapter **awareness and understanding of the changes,** understanding the impact of bvFTD seemed critical to developing appropriate strategies to support the person living with dementia. Furthermore, it appeared that the role of the closest family member was crucial to developing and implementing these processes. In spite of their different perspectives on adapting to bvFTD, Mollie, Melinda and Kate utilised similar approaches to supporting their husbands. This appeared to begin with establishing routine and structure to the day. For example, Mollie described the use of a diary to support and structure her husband's day from time point 1:

> *Mollie* *Another thing was asking questions. He was: what time are we going to be there? What time have we got… Or where are we going today? And suggestions like [OT] and [specialist nurse] the diary – the diary is like a lifeline to you now – that took away a lot of stress because he doesn't ask me; he'll look at his diary. So, if we've got an appointment and I say, "Can you pop that in your diary love for such and such?" it's in there. [T1]*

The diary had become a fundamental part of Anthony's support system, such that by time point three, with Mollie's prompting, Anthony was recording his activities to act as a reminder of what he had achieved each day. Similarly Kate described the importance of ensuring that the environment was as supportive as possible, because she recognised that Alistair couldn't process effectively and therefore lost track of where things were. Consequently she had organised their holiday home in order that Alistair was able to find everything (Table 8.21):

Table 8.21 Structuring the environment	
Kate	*So he couldn't find it. That's the nice thing…that's the most relaxing thing about being [away] because everything has a home and I've labelled all the shelves in the garage and now I've stopped my mother filling things in the holes when Alistair's taken something so it effectively shuffles the shelves, I've stopped her doing that now and she now understands it's got to go back in the same place…*
Alistair	*Yes.*
Kate	*Because she understands that it's much better. […] but in [holiday home] it's so easy because everything lives in its home and everything you can get. So you go onto…and I've coded everything ((laughingly)) I went into primary teacher mode and everything's got a label. So there's a gardening cupboard. So the hand held gardening tools are in one place. The gardening tools are on the wall in one place. The household tools are on the wall in another…and everything is…so if he's looking for a drill it'll be on the tool shelf and so that's made it easier and that's what will happen here…*
Alistair	*Yes.*
Kate	*…because that's what I'm aiming for Alistair. [T1]*

Furthermore, as can be seen above, Kate had plans to ensure that their home was similarly structured once the renovations were completed, to enhance Alistair's ability to find things independently. Melinda also referred to structuring and sequencing activity in order that Bert was able to engage with enjoyable activities (Table 8.22):

Table 8.22: Structuring Activity	
Melinda	*You accept that when you can't do something. And, instead of me having to map out how we're going to do it, you're quite happy now to do that, like with the motorbike they take photographs of how they take it apart and they'll colour-code it so they know what part goes onto another. And you've been very much part of that with them which he wasn't six months ago. You tried to hide it from them. [T2]*
….	
Bert	*And in my, yeah in my mind I was thinking, 'Right if I don't want to lose something you can sit there and become a zombie and lose it naturally if you like, if you don't use your mind, if you're not active and try and do things as best you can…'*
Melinda	*We've done loads haven't we?*
Bert	*It's got to help.*
Melinda	*We're building a motorbike, you're building a motorbike with Idris*

	aren't you?
Bert	*Yeah that belonged to one of me sons that died.*
Melinda	*Yeah they're building that back up.*
Bert	*So we've stripped it down now and…*
Melinda	*Taken photos so he knows where…*
Bert	*Had it shot blasted and undercoated and then it was…in the end, then next spring we're going to get it sprayed then silver, the proper colour and then all my lads know motorbikes so we're going to build it back up and it's 25 years old now the bike so, you know, but it's something like that that, you know and you've got the lads round doing things and they have a good laugh and a joke and all this, it's good for me. [T2]*

As can be seen from the above quote, breaking activities down into their component parts was fundamental to facilitating successful activity. Preparation and prompting was critical to this, as can be seen in the quote below where Rachel Perrin described how she had supported Alistair to engage in some work on the outside of their home (Table 8.23):

Table 8.23: Preparation and prompting

Rachel	*Well he's done a lot more of the building work and stuff. […] He dug a hole outside and he'd also hurt his back at the same time and he'd got in the hole and then I said to him, "Right have you got everything?" and he went, "Yes, yes, yes." […]. So I said, "Go through what you need and just to double check while I'm here," and he went, "Okay," and he said, "I've got my pencil, brilliant, got the pipe," and I said, "What about what you're cutting it with?" because I could see his saw was on the other side of the garden ((laughingly)) and he went, "I'm using my electric saw," and I went, "Right, where's the electricity coming from?" So he'd got the electric saw and no power ((laughingly)) supply. So he's like, "Oh, yeah I need a power supply," so I was like, "Oh right," and he told me where it was. So I went and plugged it in and brought it to him. So that was fine. And then he needed something else and he was like, "Oh ((sighs[…]. And I was like, "Right now what do you need?" and he was telling me and I was like, "And so do you need that?" that was something else that was in the garden and he was like, "Yeah," and I went and got that ((laughs)) […] And I was like, "Right! Let's help a bit here," because he hadn't…he'd thought of what he needed but he hadn't thought of the actual ability to get them [T2]*

Rachel seemed to recognise that her Dad was unable to process sufficiently to be able to plan and prepare for the task, consequently she was able to

help him to the extent that he was then able to undertake the task, through prompting and guidance.

As can be seen in tables 8.21 - 8.23, it appeared that Melinda and Kate had sought to collaborate with other family members to facilitate this structure. Furthermore, Melinda and Bert's quotes (Table 8.22) also attest to the process that they have had to go through to enable these strategies to be put in place. It appeared that Bert was not initially happy to accept this help; consequently she recognised that it would take time to put these processes in place. Melinda described the importance of learning how to approach Bert:

> *Melinda* *If we keep with a routine. At first, I used to get frustrated with him because of the changes and I know he's a capable man, so suddenly a complete change in personality with Bert and it was very difficult for me and that caused friction between us, didn't it? Now I'm able to understand what the problem is through the diagnosis, then I don't expect the same from Bert that I did before and I know I have to explain things more. I know that when he's going to do a task, we sit together and we work that task out from start to finish and we kind of do it on a board. I understand he's embarrassed about his condition, so if people come, we take away things that are reminders for Bert. [T1]*

Therefore by time point 2, Bert appeared to value the support and assistance he received from his wife and his children. Indeed he had extended his willingness to accept help to receiving assistance from a neighbour who was helping him to grow vegetables. Sensitivity to the person's experience was also evident in the Burton and Perrin family narratives.

Similarly, empowering the person to engage in activities appeared to be an important feature of scaffolding. Empowerment involved all of the scaffolding processes described above. Furthermore, it required that family members were able to undertake assessment of risk and manage activities accordingly, on an ongoing basis (Table 8.24):

Table 8.24: Assessment of risk	
Mollie	*And I'd been going out, I was out last week, I went and met [friend], didn't I, for a coffee. Left you to it. Because […] He's got a tracker. He's not going to go far because he's happy here in his own little space. And if he does wander off I can find him. […].*
Anthony	*And talking on that side, it makes a huge difference. The fact that I've got the tracker means that if, say, Mollie's gone out and I'm on my own and then you suddenly feel like you'd like to pop round to have a walk down by the river or something, that without it I would have to stay at home because if I wasn't here when she got back, then, it's upsetting. But because I've got that, then I've got the freedom to go out any time I like. [T3]*

It seemed that tolerating risk involved emotional and practical considerations. Mollie had described concerns about leaving Anthony alone, but on the advice of their GP and specialist nurse, she had felt able to do this. Achieving this was clearly beneficial to both of them in providing much needed time apart. However this was possible because of the availability of assistive technology that allowed them both to feel secure that Anthony could be found should anything go wrong.

A number of other coping processes appeared to be utilised in scaffolding. Simplification of household items appeared to be important, as described previously in chapter 7 (Table 7.21). Anticipating and managing potentially difficult situations were particularly important given the difficulties people with bvFTD experienced with control, safety and security. For example, in chapter 7, (Table 7.10) Bert and Melinda described how Bert could lose his temper when out shopping or in similar situations. In this context they had identified the triggers and worked together to agree a way of coping that involved avoiding similar situations:

Melinda: That's one concern he has, that's why he wouldn't dream of going off on his own shopping. If we go out, [where], there's more shops, he would never go in a shop, he would stand on the outside, because he says, 'I haven't got to face any confrontation.' Because I think slowly you've realised ...

Bert: *That's why I don't like answering the phone, because at the end of the day, you can say nine times out of ten, you're going to have to make a decision or say something that could cause a problem. I just don't do it. [T1]*

Rena and Dave also described the importance of ensuring that familiarity was established should Alistair need to go to strange places. With Rachel's upcoming wedding, they sought to ensure that Alistair was familiar with the place where the reception was happening (Table 8.25):

Table 8.25: Facilitating familiarity

Jenny	*So how did that come about, in the sense that, was that a process that Kate put in place?*
Rena	*Yes. We went up there the one night, Rachel and Mike, Dave and I and Kate and Alistair and had a meal up there and spoke to the proprietor before it was all booked. And Kate explained the situation and we'd taken over the hotel. […]So and then Kate said "Would it be possible for me to bring my camping car?" And the guy said yes.*
Dave	*So they parked it in there*
Rena	*So they parked it in and that was deliberately done in case Alistair found it was all too much. And, he didn't have to cope with a strange bedroom and a strange place that he wasn't familiar with. Because all the things they do at the moment, I mean, when they go [to their holiday home] they go on the same ship. They know the cabins, they know the layout, it's all familiar and they get [there] to their own house and they know where they're going. So he copes with all that. A lot of the time when they go away they go visiting with friends, they take the camping car and again, they stay there, so he isn't forced to then cope in somebody else's house. [T2]*

Through careful preparation, including engaging with the owner of the hotel, it appeared that they were able to help Alistair to feel secure and safe. Furthermore the above quote appeared to allude to another coping process, that of having a safe space to escape to. It seemed that having the opportunity for time out was an important feature of enabling the person with

bvFTD to feel safe and secure and therefore avoid stressful situations. Mollie referred to this in her description of Anthony's need to withdraw on a bad day:

> *Jenny* *So what do you notice about a bad day?*
>
> *Mollie* *Oh yeah, he shuts down and he's in the chair and he can spend hours sitting in the chair. I just leave him to get on with it basically. [T3]*

Similarly Kate referred to the importance of their holiday home and motorhome as safe spaces for Alistair. Finally, Melinda highlighted how important it had been for them to have a home with two bedrooms, so that she could give Bert some space when he needed this. Furthermore, she highlighted that it had been important to help their children to understand that he needed this space to withdraw in order to manage when the environment became too much for him:

> *Melinda* *Things like family parties, family get-togethers, if more than one comes, he'll take himself off. And it's these now understanding that's not dad not wanting to be part of it, but dad needing his space. And by doing that, these now are picking up on their children and what behaviours can trigger Bert to lose it, so to safeguard these, because all these know is that granddad is poorly and that's the way that it's been put over to the younger ones. The older ones know and ... [T1]*

It seemed that Kate, Melinda and Mollie were able to reframe behaviour as reflecting their husband's need for a safe space. However it appeared that for Mollie, this reframing was challenged by an increase in Anthony's withdrawal at time point three. Similarly Kate reflected on how lonely her life had become in the evenings as withdrawal into 'Alistairland' became a feature of their lives together:

Alistair *“I should be... hang on, what am I doing?” Yes, I've gone off into what we call Alistairland, you know, drift off and...*

Kate *I think the absolute hardest thing for me is the silence. Because I'm so communicative I find it really hard. Alistair can sit all night and not speak to me. Not because he doesn't want to talk to me, but just because he's just tired and so he's shut down. That's happened more and more and I find it quite lonely. [T2]*

Thus even though they understood the need to withdraw, it further accentuated the losses they were experiencing as a consequence of bvFTD.

Enabling and facilitating: *An enjoyable life*

It appeared that for three of the families (Burton, Morris and Perrin) seeking opportunities to continue to enjoy life was an important aspect of living well with bvFTD. Initially the onset of bvFTD appeared to impact upon what might be possible and some had made decisions to restrict or disengage in previously valued activities:

Jenny *How has that changed now?*

Anthony *What we was really, really looking forward to was retiring and actually doing some long-term cruising on the boat. That unfortunately never came to fruition and never happened, which was disappointing. Not having a boat we miss terribly. It’s a little bolthole, a little escape, a second home. We had one for such a long period of time that we definitely miss it. [T1]*

It nevertheless seemed that over time families sought to find ways to achieve opportunities to enjoy life, either by adapting activities or engaging in new ones. For example, Mollie and Anthony described finding a way to continue cruising (Table 8.26):

Table 8.26: An enjoyable life	
Mollie	*We'll see how things pan out when we go on the boat, because I think it's going to take us back how we were when we were on the smaller boat, […]. It's what you wanted. But to see him on the back of a boat, as I say, it's stepping back before he was ill. That's how he is on the back of a boat. So because he's remembering everything, what we used to do […]. Which I was quite surprised about actually, when we went out in May. So it's not "Don't give up." Like, we sold the big boat because I couldn't cope with that big boat with him. I just couldn't handle it. Then I thought we wouldn't buy another one because I don't know how he's going to be. Well, we don't. And I'd have to cope with it all. So this year we've tried hiring. And I thought "Well, hire one a couple of times a year." It's still the cost of moorings and whatever. And we haven't got the thought of, stress, the worry, the upkeep of it.*
Anthony	*It's not the same as having your own boat. Advantages both ways.*
Mollie	*No. But you love it on the back of that boat. […] But I was quite surprised when he got on the back of that boat how he remembered what he used to […] So I went through with him. He was fine, weren't you love.*
Anthony	*We find the boat very therapeutic.*
Mollie	*Yeah. You sit for hours on the front deck watching the fish.*
Anthony	*It gets rid of all your problems, just veg out. It's so calming, it slows you down to such a pace.*
Mollie	*And I haven't got to watch him on the boat. I can sit there and read the paper and he's just tootling around and he sat on the front deck for about two hours with a bit of bread watching the fish come up. […] [T3]*

Similarly, Kate Perrin described engaging in activities that they enjoyed together (c.f.p.206). Engaging in such activities required that families anticipated and prepared, managed risk and used the scaffolding processes described previously. For example, in the quote above, Mollie referred to hiring a boat rather than owning one, thus having less responsibility for upkeep, which appeared to be an important adaptation for them.

Enabling and facilitating: *Humour*

Additionally, humour also seemed to be a method of coping for some of the families. Laughing about the difficulties rather than at the person seemed to be critical to this as in the example below:

Anthony Yeah. I can behave meself if I have to.

Mollie People think 'She's telling him off.' But he takes notice. Or he laughs at me.

Jenny Like you're doing now ((laughs)). What does misbehaving mean then?

Anthony It's like being a naughty child. You go into your second childhood, don't you, when you get older.

Mollie This is why I have to keep...

Anthony You're allowed to misbehave now and again, I've got a good excuse.

Mollie He doesn't see danger, do you love.

Anthony No.

Mollie Everything's funny. We've got a saying, haven't we. 'Behave yourself now.' 'I'll come up there, I'll slap your legs.' and you'll suddenly come back and say 'Oh yes please!' ((laughs)). Everything's funny to us. [T3]

Thus it appeared that laughter enabled them to defuse a situation that might otherwise have been stressful. Humour also featured in the narratives of the Perrin and Morris families.

Enabling and facilitating: *Supporting, informing and involving others*

Over the duration of their involvement in the research, it appeared that some families sought to involve others in their lives as a means of coping with the impact of bvFTD. The Perrin and Burton families seemed to involve others in providing meaningful activity and occupation for the person living with bvFTD (Table 8.27):

Table 8.27: engaging with support from others	
Kate	*The other day when I went off with mum I spent the whole day, because it was Alistair's first time with [support worker] and I was anxious but I thought I've got to let him do it […] So mum and I went out for the day and I was climbing the walls by the time I got to [city] and she kept saying to me, "Do you want to phone?" "No I'm not going to phone, I'm not going to phone he knows where I am he can phone me if he needs me. I've got to trust that this is*

	going to work," and when I got back you'd had a lovely time you and [support worker] hadn't you?
Alistair	*Yes.*
Kate	*And he hadn't needed me at all. […]*
Alistair	*The first time we just went out where I go wind surfing and we had a walk round the lake and that and just a natter and then stopped and had a drink in a pub, a nice little pub and a bite to eat, a sandwich. And so just getting to know each other. This time we're going off to have a game of squash.*
Jenny	*Great.*
Alistair	*Yes I haven't played squash for I don't know. ((laughs)) […]*
Jenny	*Okay. So what's the reason behind [support worker] coming? Why is that happening?*
Alistair	*It's so I get to know [support worker] before I got totally forgetting people so he's familiar with me now. […]*
Kate	*The idea is that until Alistair stops working that he sees [support worker] roughly once a month to start building a good relationship because I want it to be somebody, not only Alistair trusts but that I trust with Alistair because that's hard […] I don't want five or six people. Alistair's frightened of new people. He doesn't like it. So to have a different carer coming in that's not going to work […] it's not just about the person being cared for it's about the trust that the carer has to have. If I don't trust the person there's no way I'm going to leave Alistair with them, no way, any more than I would have left a child with a carer that you didn't trust. […] Another problem is that everybody sees dementia as Alzheimer's, people don't recognise the different forms and therefore the different strands within it." He's got Alz—I mean the number of times people say to me, "He's got Alzheimer's," no he hasn't got Alzheimer's and there is a huge difference. […] But what Alistair needs is the continuity. He doesn't like new spaces, he doesn't like new people, he doesn't like lots of people. There are all sorts of little things you no longer will…*
Alistair	*Tolerate. [T3]*

As can be seen from the quote above, it appeared that in order for these opportunities to be successful, they needed to focus on activities that the person with bvFTD would enjoy and was willing to engage in. It seemed from Kate's narrative that this was also designed to support Alistair to become familiar with others being involved in his care, as dealing with strange people and places was a particular difficulty for him.

Furthermore, it was additionally important that the family were able to trust that the care provided would be beneficial and that they could trust the person involved. This commonly involved ensuring that the support worker

understood the person's specific needs and as indicated above, recognised the way in which bvFTD might impact upon those needs. Kate also referred to the importance of developing a relationship with the person to support greater involvement as Alistair's needs increased.

A particular benefit to involving others in the person's care appeared to be the opportunity for time apart as a number of the families mentioned that one impact of bvFTD involved spending increased amounts of time together. Therefore, although initially Kate found it difficult, she subsequently identified that having time apart was an important benefit of such support.

Distancing, managing and controlling: *getting through the necessities*

However, as described in the sections **awareness and understanding of the changes** and **we're not the same anymore**, the Hugh and Lewin families appeared to position the problems brought about by bvFTD with the person and seemed to distance themselves through processes such as care management. This strategy was only partially successful; consequently these families also seemed to limit their involvement to getting through the necessities of life with the person with bvFTD (Table 8.28):

Table 8.28: getting through the necessities	
Pamela	*And I was getting more and more worked up because of the amount of stuff that I've gotta do that I was thinking 'I just can't do this anymore.' So it's a bit like I've had to look at it and say 'Well, as long as she's got her basic needs...' The carers are going in, I'll go in when I want to, or when I have to go in. But you see, when I back off, she ends up phoning me. So it's like ((laughs)) "Oh, Pam hasn't been round for a week or two. Ooh, let's try ringing her!". And it'll be ridiculous things that she's phoning for. Well, nothing in particular.[T2]*
Sarah	*Yeah we're just getting through the day by doing the necessities with him, so eating, drinking, toiletries, [T1]*

It seemed that this strategy wasn't entirely effective for Pamela as she felt her mother would re-establish contact if she hadn't been there for a while. Similarly, it had limited success for Sarah and Alex as they lived with Ray and were therefore exposed to his needs for much of the time.

Distancing, managing and controlling: *controlling them and others involved in their care*

Additionally, it appeared that both couples engaged a controlling approach to manage the behaviour of the person with bvFTD.

Sarah and Alex initially utilised a strategy of keeping Ray in check. This involved being firm with him about his behaviour:

Sarah *You have to be quite strict with him.*

Alex *'You have to do it my way,' rather than his way, because sometimes he just will not listen. And I've only raised my voice to him once, but it seemed to work for about six months and I didn't get any backchat. [T1]*

However, over time they seemed to become less controlling in their responses to him (Table 8.29):

Table 8.29 being less controlling

Sarah	*So I'm like, "Why do you want to swap all these about?" "Oh well I own that land and I want to make sure that that's right," "Right okay dad." So I've done it because if you don't do something…*
Alex	*He'll mither on and on.*
Sarah	*…he'll mither yeah all the time and he'll make. He'll make your life a living hell so you just…it's easier to give into him sometimes ((laughs)).*
Jenny	*Are there things that you both give in on?*
Sarah	*I try but what don't we give in on?*
Alex	*He wins on everything come on.*
Sarah	*Food to a certain point but even then I give into that. He knows he's meant to be taking it easy with what he's eating but then I think, well…*
Alex	*What pleasures in life…*
Sarah	*What pleasures in life does he have? So people are saying don't have pudding or don't…*
Alex	*He doesn't drink, he doesn't smoke, you know, if a guilty pleasure is overindulgence then as far as I'm concerned just let him. He hasn't got the options we have and it's sad but it's true so as far as I'm concerned if he wants to eat it he can.[T3]*

It is possible that lessening their use of control with him arose because of the level of support they were receiving, which was not present at time point one.

Nevertheless they continued to experience the situation as stressful and difficult because of the demands of caring for him. It seemed that at times Ray was aware of this difficulty:

Jenny *So what's things like as a family together at the moment for you and for Sarah and for Alex and the grandchildren?*

Ray *Well they might find it more difficult because of the kids […] to look after me because they've got the kids to look after. So in a way I might come…well I'm part of the family but I wouldn't get full attention because of, you know, what Sarah has said, I mean, "You're not the only one here mind." Which is understandable. The way to have full treatment is just what I'm saying if you want to go away into a home and be looked after or you can come and look…you know, I mean to say what I'm trying to say is stop in your home as long as you can, don't complain too much what they do for you, well what they do for you is a bonus.*

Jenny *Yeah.*

Ray *But don't, you know, if you start playing up too much you'll be away like, you know. That's what I'm saying you've got to be careful. [T2]*

It appeared that Ray recognised the need to control the demands he made on them in order to avoid placement in a care home. However while he may have shown some level of cognitive awareness in interview; Sarah and Alex continued to experience his behaviour as difficult, suggesting that from their perspective, he didn't control his behaviour 'in the moment'. By time point three they had made the decision that there were limits to what they could do to support him:

Jenny *Okay. So you were just saying that it's quite difficult for you to manage the challenge of looking after him and the children when you're on your own?*

Alex *Yeah, which is becoming obviously it's more often but it's a case you have to but we've had another incident with a near fall so since then it's a case of I'm just not going to take that*

risk any more. So whether it be he unfortunately has an accident in his trousers then so be it and he'll have to have a pad and that will be that because I'm not having another incident like we did with the paramedic here the last time.

Sarah *Yeah we had the paramedics here again since you've been.*

Alex *And it's yeah it's a no-no. [T3]*

While it seemed that this was due in part to other life circumstances, including their children's needs and their own health challenges (c.f. chapter 6) it nevertheless resulted in coping processes that continued to position Ray as at fault. However, although their situation was very difficult, Sarah and Alex seemed unwilling to contemplate alternatives:

Sarah *Yeah if we have too many things going on that they're going to turn round to us and say you can't cope he's got to go into a home.*

Jenny *Is that something that you've talked about?*

Sarah *Other people have but we haven't because that was never the, you know and the going gets tough sometimes but he's not ready for a home yet, I feel yeah that he'd be ready for a home when he has to have feeding […] or whatever […] but whilst he's like he is I think that we can cope with it. We get support, carers, so yeah. [T3]*

Pamela and Jonathan also appeared to use a controlling approach in their response to Elizabeth. Taking control seemed to begin during the pre-diagnostic phase as a consequence of the level of risk that became apparent. Furthermore it continued throughout Pamela and Jonathans' involvement in the research. As a consequence of the difficulties experienced prior to diagnosis, taking control involved managing care to ensure that Elizabeth's needs were met. They appeared to feel the need to do this as a result of the challenging consequences of Elizabeth's behaviour for her well-being, their own and others. However, managing her care commonly involved damage limitation as they frequently found it difficult to control Elizabeth's behaviour or indeed to mitigate the consequences.

They had discussed Elizabeth's alcohol intake at length on more than one occasion. In the following quote, they described the challenges of managing this difficulty and addressing her best interests as well as managing the dilemma it created for them;

Pamela *So she was drinking really heavily. I don't know quite at what point we stopped her from going to the shop.*

Jonathan *Well I don't know but we looked at it from our point of view and said is it morally right to be supplying this to her because if she dies of alcohol poisoning or as a result of drinking that's been supplied to her by us, on the advice ((laughingly)) of the psychiatrist but nonetheless we've been kind of aiding and abetting so we were quite ready to pull back on that weren't we? [T1]*

They appeared therefore to be trying to protect Elizabeth, which frequently involved making impossible choices, as a consequence of dilemmas for which they had no satisfactory answers or solutions.

Damage limitation also therefore seemed to involve attempting to control and anticipate what Elizabeth might do or what she might need. Additionally it involved managing the risks associated with her behaviour, even though they acknowledged that this was also difficult to achieve. They described the need to manage her life in the first interview and continued in this vein, suggesting that they needed to control everything. This included the care package, the frequency of her trips to the shops with the carers, the amount of alcohol she consumed and her meals, as described in chapter 7 (Table 7.13). Pamela and Jonathan therefore described many different activities involved in controlling her life, much of which required a supervisory role, overseeing and monitoring on an ongoing basis.

For both families, controlling also involved managing the work of others involved in providing care. Sarah and Alex described the necessity of ensuring that the carers understood what they needed to do for Ray:

Sarah *[…] I've got a situation at the moment that could be really dangerous and why they don't do it I don't know. He has a stand and turn you've seen them the plates and I saw it with my own eyes and I, excuse me, [told him off] him after it happened. Two skinny girls, bless them, came and put him to bed the other night and he got on this stand and turn and messed around and he started rocking it. Well, they nearly lost control over him and he so very nearly ended up on the floor. […] I said, 'You've got to tell him, because you're going to get injured, or he is,' […] you have to go in really firm with him.[T1]*

Similarly, Jonathan and Pamela frequently described the need to direct the carers in their interventions with Elizabeth.

Avoiding and reacting: *blaming and undermining*

As with the Hugh and Lewin Families, it appeared that the Stuart Family also positioned Terry as the problem and seemed to see him as responsible for his behaviour. While Carole seemed to move to a position of being more understanding of his behaviour by time point three (c.f. table 8.6) it did not appear that Sue was able to make a similar shift in her understanding and therefore her responses to Terry. Consequently, Sue's responses to Terry's difficulties appeared largely reactive and critical as described in chapter 7 (Table 7.4). As a result, it seemed that Terry became frustrated and upset with Sue and may have felt undermined by her as suggested by Carole:

Jenny *Right and that's been quite a change really?*

Carole *He does shout at her quite a lot I think. "Stop telling me what to do," I think she does treat him like a child and sometimes I do cringe. But it's like, oh. But I just…I suppose she's just so used to having to tell him what to do. It's something very difficult a balancing act I would imagine ((laughs)) [T3]*

Furthermore, as described earlier (p.228), while it appeared that Sue had received support in the form of a specialist nurse, this did not appear to have influenced her approach towards Terry, indeed she did not mention this

support when discussing what had helped her to cope. Therefore Sue mentioned few coping processes throughout the research, with those used being largely confined to having to bite her tongue and let it go or walking away when they got into conflict (Table 8.30):

Table 8.30: having to bite my tongue and let it go

Sue	*I'll tell you what else he does. We can probably be going in the car and we might start talking about something and then all of a sudden Terry comes out with something which is not anything to do with what we've just been talking about.*
Terry	*That's the editing listening.*
Sue	*And I go, 'What are you on about?' 'You know I can't.' And I just don't know what you're on about you see! ((laughingly)) But he expects me to think what it is. That has caused a few words in the car. Nearly every time we go out in the car we have a few words! ((laughs))*
Jenny	*So it's what you were saying about the editing machine?*
Terry	*It's the editing machine. My brain is engaging to that editing machine and it goes on something that I'm thinking about and it edits that. And the brain goes ten to the dozen, thinking of something else and I'm trying to get that across and it's quite frustrating, isn't it?*
Jenny	*It sounds like it's frustrating.*
Sue	*But no, you're expecting me to know exactly what you're thinking of at the moment and I think, 'Well, I can't see any relevance to how he's come out with that when we've been talking about something entirely different!' ((laughs)) So now I've got to try to bite my tongue every time he does it and not say anything, but it's very difficult, isn't it?*
Jenny	*It sounds like it's frustrating for both of you.*
Sue	*Yeah, yeah.*
Terry	*Yes it is, Jenny and I'm not stupid, I know what I'm trying to get across and if you can't get it across it's frustrating. [T3]*

It therefore seemed that Sue was somewhat passive in her responses, reacting only when situations became difficult.

Avoiding and reacting: *finding ways to enjoy life while we can and involving others in care*

Sue and Terry's primary coping approaches as a couple appeared to be limited to finding ways of enjoying life while they still can and continuing with the support of a carer for Terry. They described engaging in activities that they enjoyed together (c.f. table 8.13) which appeared to be particularly important to them as a way of coping with the impact of bvFTD on their lives:

Sue *I keeping trying well just make our life as best as we can and that sort of thing and that's the only thing you can do isn't it really. I mean we still have a laugh and a joke don't we?*

Terry *Yeah.*

Sue *and do that you know.*

Terry *I laugh at her and she laughs at me. ((laughs))*

Jenny *So how do you make life as best as you can, what do you do?*

Sue *Well by going on holiday, trying to keep in touch with our family and things like that. [T1]*

Furthermore, as with the families that engaged in enabling and facilitating, it seemed that they felt that humour was also an important coping process. However as described previously (Table 8.13), it did not appear that the holidays that Sue and Terry took were always successful as Sue felt that Terry was not as supportive of her as she needed him to be.

Sue and Terry also described having a support worker for Terry, which enabled him to be motivated and to engage in meaningful activities:

Jenny *So this was the person who was coming to take you out?*

Terry *And don't forget that fellow.*

Sue *We were supposed to be getting funding and the only help he's had is this [carer] that comes and it's [a care agency] and he's a really nice chap and he's even helped Terry decorate the kitchen and the dining room, they did it between them, because I was worried and I can't cope now with scraping paint and whatever, so they did it between them*

and it looks lovely. I mean they did that dining room in half a day and we hadn't moved anything, so that was nice and they enjoyed it. I put music on for them and they were singing and laughing and he enjoyed that. And then like last week, he went to play snooker with him and I went into town.

Terry *He's £50 a time, mind you.*

Sue *He enjoys that, Jenny and that's what he needs. [T3]*

Again, as well as providing meaningful activity for Terry, an additional value of this appeared to be in providing Sue with time apart from Terry (c.f. p.231).

8.5 Being me in the context of bvFTD

The challenge of being me in the context of bvFTD was experienced by all five people living with dementia who participated in this research. People living with bvFTD experienced challenges to self, identity, agency and safety in the context of the social and cognitive changes brought about by dementia.

The coping processes utilised to address this challenge involved strategies that the person with bvFTD invoked as well as those that family members developed. In some families, there was collaboration within the family including the person with bvFTD which seemed to support selfhood, agency and to maintain wellbeing. This appeared to include 'holding' the person to manage feelings of distress. However, in other families, individual family members seemed not to recognise the difficulties the person was experiencing, thus the person with bvFTD appeared to act independently to attempt to maintain selfhood, agency and wellbeing. Evidence of coping processes associated with this challenge occurred across all three time points. A number of subthemes emerged from analysis:

- Maintaining self
    - I'm still me, still active and engaged with life;
    - I'm still me, there's nothing wrong
    - I'm still me, resisting negative perceptions
- Maintaining wellbeing
    - Supporting safety and security (a collaborative process)
    - Holding them (family members)

To;

- Resisting and restricting (person with bvFTD)
- Positioning, controlling and distancing (family members)

Maintaining Self:

I'm still me, still active and engaged with life

Alistair Perrin and Anthony Burton appeared to acknowledge that they were changing and recognised that their family members may have different perspectives on how much bvFTD had affected them. It nevertheless seemed that they engaged in activities or roles which maintained their self-concept and therefore selfhood. Alistair and Anthony referred to valued aspects of their lives that they continued to engage in which appeared to reinforce their sense of self. For example, Alistair had initially reflected on the importance of children in his life, which was reinforced by his family, (c.f. chapter 6). He continued to reflect on the positive nature of his relationship with his grandchildren:

Alistair	*Yeah. The kids get my attention straightaway.*
Kate	*They always have done.*
Alistair	*Yes.*
Kate	*The little ones always do.*
Alistair	*When they come in and they're in your face really they don't have certain…*
Kate	*And they're loud and they're not subtle you see, "Grampa you're not listening!"*
Jenny	*((laughs))*
Alistair	*Yeah wallop, "Grampa!" okay right. ((laughs))*
Kate	*"Grampa!" she's pulling on his legs, "Grampa!" [T1]*

This relationship continued to be important throughout his involvement in the research. Similarly, Anthony was described by Mollie as someone who would always try to help others (c.f. chapter 6). He continued to value opportunities to contribute for example, undertaking activities such as work with the University and as in the example below, for the church rooms (Table 8.31):

Table 8.31: Continuing to contribute	
Anthony	*[…] So I've been well pleased with that, how I've been coping and standing up. And a few improvements as in doing a bit of voluntary work over the church rooms, has given us a good sense of purpose.*
Jenny	*How did that come about?*
Anthony	*The treasurer of the church rooms, ... he was cutting the hedge back running along the pathway, the alley there and the hedge had got so tall and overgrown he couldn't reach the top of the hedge, […] And he was doing it all on his own. […] Talking to him over the garden fence, we give him a hand on occasions and used our brush saw to cut down a few of the big trunks of the holly trees in the middle. And that's how we got involved. […] So that's made a difference to us, doing something that... We walk past every morning, going down for the paper, so you see the gates that you've done, you can relate nicely to it. So you're doing it for your own benefit really, not for anybody else. [T3]*

Thus they appeared to be able to maintain their sense of self and remain actively engaged with life in spite of the changes they experienced. It appeared that for both Alistair and Anthony, the responses of family and others around them supported the maintenance of self-concept. For example, both the Perrin and Burton families reinforced Alistair and Anthony's identity as a grandparent throughout the research (Table 8.32):

Table 8.32: Supporting selfhood	
Kate	*Yeah. Oh yeah, yes. Child safety has always been... But he was like a magnet at the wedding. All of these kids, […] everybody's small person and there were a number. There were only fifty at the actual wedding and twelve of those were little people. So he's playing with them all at the bottom of the garden. Weren't you?*
Alistair	*Tag. Tickle. Wizards.*
Kate	*Because they just played with all these kids. Had a lovely time.*

	Every time we looked up he was playing with the kids. [T2]
Mollie	*She is, honest to God. And they're both the same with him. And he loves it, you love it, don't you. And another thing he does with Isla, I leave the front door open now she's here. The horror! Wild child! He goes out and he does the same with her, she'll go out and she'll 'Come on Granddad, we're going out for a walk in the garden.' And then you'll hear the doorbell going. And she's got him to lift her up so she can press and you open the door and she's smiling. And they keep going round and round.*
Anthony	*That's true, straight out the back door and then straight round she comes to the front door.*
Mollie	*Granddad's got to lift her up, so yeah, she's been up when you had potatoes, growing potatoes at the back. She gets her hands dirty, she enjoys that, Isla. Chloe doesn't. Chloe does not like getting dirty at all. But Isla loves it. So he really has some fun with the girls, don't you. They're very caring. [T3]*

Relationships with their grandchildren appeared to be viewed positively and supported by both families. Both Kate and Mollie appeared to recognise that the ability to engage in more complex activities with the grandchildren was changing over time and as described previously, (p.159-60) Alistair and Anthony appeared to find it easier to interact with younger grandchildren. Nevertheless, it seemed that these relationships were maintained throughout their involvement in the research and held benefits for both the person with bvFTD as well as their grandchildren.

Similarly, both Anthony and Alistair were supported to engage in and be successful at activities through enabling and facilitative strategies described earlier in this chapter, such as scaffolding. For example, Anthony was no longer able to drive. Consequently, Mollie supported Anthony to attend meetings at the University and facilitated his engagement with activities associated with this. Similarly, throughout the duration of the research, Alistair continued to work as a result of a partnership between his employer, Kate and himself. This involved Kate supporting his manager and work

colleagues to understand the nature of the difficulties he experienced and the adaptations he needed (Table 8.33):

Table 8.33: Supporting and informing others	
Kate	*So that's when they panicked and we went to Occupational Health, which was fine. It was quite interesting that the doctor that was the occupational health guy was asking me about what he could do and I was explaining all the things that he couldn't do and what the condition does and how it's going to degenerate. And I looked at him at one point and said, 'You're the doctor, why am I telling you?' And he said to me, 'You've got a greater understanding and knowledge of this than I do, because I only know what I've read on the internet, when I knew I was seeing Alistair.' And I said, 'And you will have read Alzheimer's and he doesn't have Alzheimer's and there is a huge difference.' And he went, 'Right, which is what you're explaining to me now.' So he wrote his report, […] What we've got to now, is if they're going to change something drastically, the arrangement is they will contact me first. And then he came home yesterday and said they're changing his boss again, but they haven't contacted me, which is a bit of a worry, because that is what we'd set in place to work, so that I could prepare him for it, because it is best. If we know something has got to change, it is best it comes from me, isn't it? [T1]*

Furthermore, when Alistair's driving licence was withdrawn, Kate explored ways of enabling Alistair to continue to go to work through employment support allowance.

I'm still me, there's nothing wrong

This subtheme primarily appeared in Ray Lewin's narrative, although the Hugh family seemed to feel that Elizabeth held a similar perspective. However as Elizabeth did not take part in the research, it is not possible to present her perspective here.

Ray seemed to hold onto a resistant self-concept in which he largely refuted that he had bvFTD.

> *Ray* *I've seen a lot worse people with in homes than me i.e. dementia which I suppose I've got but it's not showing up on me yet [T1]*

This appeared to be due to lack of awareness as well as a lack of emotional engagement as a consequence of the impact of bvFTD. Ray's self-concept seemed to reflect who he perceived himself to have been throughout his life, as demonstrated in the quote below:

> *Jenny* *So how has life changed for you?*
>
> *Ray* *Well I've made life go on. They always say to me now and I've had MND for, well been diagnosed nearly 15, 16 years. Now when I was really active, which I've told you I was an active man, picked a tennis racket up during the Wimbledon, played cricket, mowed pitches, played crib, played darts, played well everything and so it came very hard for me when I was called MND like a sledgehammer. They said, "What is MND," and I said, "Well just think of a sledgehammer on top of your body, you want to get up but you can't." And people said to me it must have been very, very difficult for you Ray. But I comes out with it. And I've kept smiling and I've kept eating. [T1]*

Furthermore, where he acknowledged changes, he focused solely on the physical and emotional impact of MND, but stressed the importance of maintaining a positive view despite those changes. This unchanging self-concept is held despite the significant changes that Sarah seemed to feel had occurred, indeed at the first time point she indicated that he had fundamentally changed from the person she knew:

> *Jenny* *So how has he changed, what's he like?*

Sarah *Oh, he's very argumentative now and he never used to be, everything's all about him. 'It's mine.' It was going on with the budget today, there was a penny off the price of beer, oh my God, if that had happened years ago, he would have been over the moon and now he's going, 'No, tax them!' and re-re-re. You just think well you're, everything that he was, he now is the contrast of, in my opinion. [T1]*

Therefore despite the changes associated with bvFTD and the way his family appeared to view and respond to him, it appeared that Ray believed that he was the same person he had always been.

I'm still me, resisting negative perceptions

Terry and Bert appeared to have a tenuous self-concept which was influenced by their concerns about stigma and the negative perceptions of others. They seemed to need to defend themselves from the perceptions of others.

For example, Bert and Melinda described the difficulties Bert appeared to have with others knowing his diagnosis (Table 8.34):

Table 8.34: Stigma and others attitudes towards dementia

Bert	*But also it's an eye opener, that the four years we were on the other scheme […], the people that hadn't got issues, like a lot of them that we knew, when we first moved on there, had got dementia.*
Melinda	*But afraid to say. […]*
Bert	*And it's the same on here...*
Melinda	*It's different here.*
Bert	*Yeah, attitudes are different, but what I'm saying is ...*
Melinda	*You're afraid of how people are going to treat you if you tell them, that's half your problem, isn't it? Because it's like Bert had mental health issues, he had a breakdown when he was 49, a really bad one and if you tell someone you've got mental health issues, the whole ... ((laughs)) the whole [conversation] finishes and people tend to shy away from you, so we've been dealing with that for a*

	few years. And dementia is very much the same in that people don't understand. 'I'm still me, I'm still Bert,' and you find it hard to deal with how people then react to you. One friend that we had, that we thought was a friend, we'd just found out he'd got dementia, we told them and that was it, we've never seen them. And Bert is very afraid of isolation, if you like, of people and the way they treat him. Where you go to lunch here, once every other week, you go for the lunch and people accept people for what they are, but you really are afraid of saying, 'I've got a form of dementia,' aren't you?
Bert	*Oh yeah, yeah. […] It's like cancer was 15 or 20 years ago.*
Melinda	*You didn't talk about it. [T1]*

He and Melinda described the stigma Bert had experienced as a result of his prior mental health problems. Indeed given the way that their friends had responded, his fears about others' perceptions of him since his diagnosis appeared to have been realised. Terry also appeared to have similar concerns about the people he lived near knowing what was wrong with him and seemed angry with his wife Sue for telling a neighbour at the first time point. Later in the research, both Terry and Bert appeared to have moved to a position of recognising that others might help and support them, consequently they had become willing to tell selected others. However, their narratives appeared to suggest that they continued to be concerned about the way others viewed them and treated them.

For example, even though he acknowledged some of the changes, Terry frequently appeared to engage in self-protective responses when talking with his wife Sue about their experience of bvFTD. During one of the interviews, Sue described Terry's behaviour towards others in the supermarket, suggesting that he was at times inappropriate in his responses, following which he seemed to respond defensively (Table 8.35):

Table 8.35: Resisting negative perceptions	
Terry	*If I was aggressive, I would say yes, I'd have something done about it, but I'm never aggressive, am I?*
Sue	*Yes, but you are occasionally to me.*
Terry	*Well, that's probably the diabetes.*
Sue	*No, I think it's the other. You shout at me. And he can't deny it, because the chap down there, he's walked past with the dog and he says to Terry, 'I heard you shouting at Sue the other day.'*
Terry	*That's indicative of the diabetes, a lot of people have that. […]*
Sue	*Terry, with you it's probably a combination, isn't it? […]*
Terry	*[…] Yeah, but [friend's] the same, [his wife] tells me.*
Sue	*Yes, but Terry you haven't always been like that towards me.*
Terry	*Oh no.*
Sue	*That is what Jenny's trying to determine, how you've changed in our relationship.*
Terry	*Yeah, I tend to be a bit stressy. [T3]*

Both the positions of I'm still me, still active and engaged with life and I'm still me resisting negative perceptions featured in Terry's and Bert's account, although it seemed that the latter was predominant. While both of their narratives seemed to have emphasised the need to resist negative perceptions, this did not preclude engagement in activities that reinforced selfhood. For example, Bert described rebuilding a motorbike (Table 8.22) and Terry described helping a neighbour out:

Jenny	*So even though it's difficult you do still do things?*
Sue	*Yes.*
Terry	*I can do most things. I can do a lady's, […] sewing machine, I took it to pieces and put it back again. So I'm not completely non compos mentis, am I? [T3]*

Similarly, there were occasions when resisting negative perceptions appeared in Alistair's account at T2 and T3, where he seemed to be sensitive to Kate's apparent criticism of his driving safety:

Alistair *I process sometimes at the roundabouts, which roundabout do I want to go so I've gone round roundabouts no end of times.*

Kate *Two or three times we've gone round roundabouts.*

Alistair *I want that junction. It's just I'm working out where I go.*

Kate *((laughs)) My mother thinks it's hilarious, another round the roundabout*

Alistair *I don't have a ((laughingly)) problem it's just another way of processing and dealing with the situation.*

Kate *However not terribly safe in a car.*

Alistair *I think it's safe, you're still moving and going round, you're not blocking anybody in, not stopped in the road and saying where am I going? [T3]*

Consequently, while all 5 participants appeared to hold to one dominant position, to a lesser extent, other positions were also evident in their accounts.

Maintaining Wellbeing

Supporting safety and security

In chapter 7, (p.174-7) examples of the experiences leading to feeling out of control, unsafe and insecure were described for four of the people living with bvFTD who participated. Two of these participants, Bert Morris and Alistair Perrin appeared to be supported by their families to utilise coping processes that supported feelings of safety and security. These appeared to include holding to routines, to familiar environments and familiar people. Holding to routines appeared to be a particularly important strategy for Bert:

Jenny *And what helps you to cope, Bert?*

Bert *I suppose getting into a routine of doing things.*

Melinda *You get very disorientated if we break that routine.*

Bert *Well, yeah.*

Melinda *We have to motivate him first thing in the morning, but once you've done that we're well away.*

Bert *But also if that's sort of broke, I do get upset then.*

Melinda *Because he feels like and I think we've all recognised this now, that Bert's very good in a routine, that you could think: oh, a bit of memory problem, it's a bit of change of personality, but when you break that routine it becomes very evident about his problems that he has got, because you're very frustrated, you get very disorientated, don't you?*

Bert *Mm. [T1]*

As the above quote appears to suggest, Bert seemed aware that routines were necessary and furthermore, when they were broken, this caused him to feel distressed. Having order and routine included that others should keep to appointment times as highlighted in table 7.22 and also seemed to involve life remaining ordered and familiar within their home. For example, when Melinda was admitted to hospital, Bert acknowledged that he found it very difficult to cope with the change:

Jenny *What was that like for you when it happened?*

Bert *Well I just couldn't get my head around all the changes that were going on.[…] Well over a period of time I'm better with a routine.*

Jenny *Yeah.*

Bert *But everything just went up in the air, so then I mean with obviously going to the hospital to see her and then your meals are changed everything changes, your your times and…so I didn't like that at all. It was upsetting. [T2]*

Alistair also discussed how important it was for him to feel safe in unfamiliar environments. He appeared to recognise that when he and Kate were out, he needed to be able to locate her in order to avoid feeling insecure and unsafe:

Kate *I mean going to Tesco at one point was absolute nightmare […] I wanted to buy a new coat and I found this really smart black one. […] "Why don't you have this one, it's a nice red why don't you have this one?" And he went on and on and on wouldn't let me have the black one and I didn't understand why and then it came out a few nights later, "Because I can't*

find you in the supermarket unless you're wearing something bright," and it was about locating me.

Alistair *Something in a different colour.*

Kate *So I mean I have a very bright red hat, my rain hat is a bright red one and I have a bright turquoise…*

Alistair *Yes the red hat's helped as well. [T1]*

In the above quote, it seemed that Alistair had been able to identify an effective visual strategy for ensuring that he could find Kate when they were out, through the use of bright colours. Even though he struggled to communicate this strategy, once they had worked it out together, it appeared to support his ability to find her and therefore to feel secure.

For both Bert and Alistair, it would appear that their partners and family supported the development and implementation of these strategies. As indicated in chapter seven and earlier in this chapter, it seems likely that the extent to which family members were able to comprehend the emotional experience of the person with bvFTD was important. Examples of this were highlighted earlier (p.204-6) and in the quotes above, where both Kate and Melinda appeared to recognise the difficulties their partners experienced. Consequently, they seemed able to collaborate with the person with bvFTD to explore ways of managing.

Holding Them

The Perrin and Morris families seemed to recognise that the person with dementia experienced significant anxiety and panic as a result of the difficulties brought about by bvFTD. Phil Horton also appeared to recognise Penny's need to feel safe. In addition it appeared that Mollie Burton recognised that the experience of bvFTD was variable resulting in good and bad days that could also lead to increased difficulty for Anthony. Consequently these families (Horton, Burton, Perrin and Morris) appeared to develop coping processes that sought to hold the person with bvFTD emotionally in order to support their wellbeing. Coping processes involved practical, emotional and physical strategies. For example, Phil Horton appeared to try and understand Penny's emotional world and discussed why

she might behave in particular ways. He felt that Penny struggled with personal care because she might have thought she was being attacked. Phil therefore described ways of supporting Penny including cuddling her in order to enable her to feel secure. He also discussed working together with the care home staff, to help them to understand her needs and support her as described earlier (table 8.9).

Similarly Kate described the strategy they had developed since Alistair had developed difficulties with sleep as a consequence of high levels of anxiety (Table 8.36):

Table 8.36: Holding them

Alistair	*Take teddy to bed.*
Jenny	*Yeah because you were talking about, in July last year and we met I remember you saying you used to get and I can't remember the word you used.*
Kate	*Night nadgers.*
Jenny	*Night nadgers that's it. You used to get night nadgers and you said that you'd done something to make a difference something to do with a teddy.*
Kate	*Yes. Teddy.*
Alistair	*Yes take teddy to bed.*
Kate	*Yes well now he's got lots of them. We have teddy that sleeps here, we have one in France that's the same size and then sitting on the sofa behind you is our suitcase travel teddy.*
Alistair	*Travel teddy.*
Kate	*Because he's smaller than the rest and he'll stuff it in the suitcase. He's not quite as good as teddy and the big one that he's got is great because it's 80cm so it's big and he just, him and the teddy, it stops the crying. It's stopped him crying, it hasn't stopped him snoring.*
Alistair	*My safety net.*
Kate	*But it's stopped him crying at night.*
Alistair	*Yes secure, it's like a comfort blanket. […] But I can't cuddle Kate all night long, which I'd like to but…*
Kate	*He's tried to and it just doesn't work, go away! [T3]*

Rena	*And you know about the teddy bear, do you? That's really worked very, very well. And much to my surprise when it was first suggested and they got it, he came out and showed us.*
Dave	*Yes he didn't try and hide it [T3]*

As was described in chapter 7, Alistair experienced panic and anxiety as a consequence of the changes in his emotional and cognitive sophistication. As his symptoms progressed, his anxiety increased and his sleep became disturbed. In conversation with peers, it was suggested that Kate try offering Alistair a teddy. Alistair was accepting of this as can be seen from the quote above and it appeared that this had a significant and lasting effect on Alistair's wellbeing at night. Furthermore it seemed to be accepted as an effective strategy by the whole family, as evidenced in the quote from Rena and Dave.

Although Anthony Burton's narrative did not suggest that he felt unsafe and insecure, it nevertheless appeared that Mollie sought to hold Anthony. She described the need to take the lead from how Anthony was on any particular day:

Mollie	*Mm. But if you're not having a good day and I say "Well, do you want to go so-and-so?" You say "No. Fine. No." […] he shuts down and he's in the chair and he can spend hours sitting in the chair. I just leave him to get on with it basically. Because he'll go in the garden, wander round, spend about a quarter of an hour in the garden and he'll wander back in, sit down and you know, you just leave him to it. Because he's quite happy in his own surroundings.*
Anthony	*You can have a busy few days and you're getting about and you're doing things. And then all of a sudden it all catches up with you and then you're totally and utterly drained.*
Mollie	*And somebody'll say "Well, why can't you come?" I said "He's not having a good day today." Well why?" And I say "Well, he just wants to be left alone today." And that's it. I just carry on and leave him to get on with it. He's happy. [T3]*

Throughout their involvement in the research, Mollie described the importance of being flexible with Anthony, recognising that he had good days and bad days and that it was important to respond to this appropriately. As described above, this meant that any activities that had been booked had to be flexible and Mollie was prepared to cancel engagements with others if she and Anthony felt that it would not be beneficial for him to go. Thus she seemed able to consider Anthony's perspective and support him.

Further coping processes used by these families to support the wellbeing of the person with bvFTD appeared to include;

- Learning and understanding about bvFTD
- Developing routines and structure
- Anticipating and addressing challenges
- Involving others in their care
- Having a safe space to escape to

These strategies were described earlier, in the sections considering coping processes for managing everyday life, awareness and understanding of the changes and we're not the same anymore. Consequently, to avoid repetition they are not described here.

Resisting and restricting,

In contrast, two of the participants, Terry Stuart and Ray Lewin appeared to use the strategy of retaining control through resisting or restricting activities that caused distress. For example, Terry appeared to experience being out of control and unsafe when driving and as a consequence he and Sue suggested that he had restricted where he would drive to:

Terry *Yeah I've lost a bit of my independence really, I mean, with not being able to drive anywhere.*

Sue *I think that's because that was one thing when we retired he said, "We'll go off to different places that we've never seen" and we haven't. All we go is to places that he already knows like going to our daughter's, going to his brother's, you know. I mean we've only been Mark once by car and it took us five*

hours because he was driving so slow on the motorway, he has a real fear now of the motorway.

Terry *You've got all these [people] and what have you and they don't know what side they're driving.*

Sue *No it's your fear in your mind, Terry.*

Terry *It's safety.*

Jenny *Yeah.*

Terry *It's safety I'm thinking about, you know, if anything happened. If anything hit you...*

Sue *I know.*

Terry *You know and you went like that you'd be dead. [T1]*

Similarly, Sarah and Alex appeared to suggest that Ray had significantly restricted what he would do since he was diagnosed with bvFTD.

Alex *I do feel for him for that because he was such an active man, I mean playing all his sport […] and socialising.*

Sarah *…and we can do things whereas he can't and he won't. He doesn't help himself.*

Alex *No and he's got to the point that just he won't, he won't. […] He won't go out of the house. We, hopefully, are going to get the kids christened on the same day and we've offered to get a special taxi here to take him to the church because he's got his electric chair and bring him home and he won't go.*

Sarah *No, well we don't know. I've said, you know, "Are you coming Dad?"*

Alex *Well we have said think about it because he…*

Sarah *So he says, "Oh well I'll think about it." Well I wouldn't have thought there's anything to think about, they're your grandkids and it's only, you know, a journey in a taxi which you've been in before... […] You can guarantee he won't but he won't…we've done everything possible over the last…well since he's become ill to get him out and about and he just won't go. [T2]*

In his interview, Ray appeared to suggest that these restrictions were as a consequence of MND. However, it seems possible that his reluctance to go out may also be as a result of a need to feel in control, as adaptations that would have supported him to travel had not made a difference to his willingness to go out. Additionally, although Ray accepted that he would go into respite care, he nevertheless became anxious when this was due to happen and had even demanded the same room each time he went, which may also have been as a consequence of his need to feel in control.

Positioning, distancing, controlling

In resisting and restricting activities, it appeared that Terry and Ray acted independently of their family members. Even though Sue commented on Terry's actions in regard to driving, it did not appear that this was a decision that was reached jointly. Furthermore, as highlighted in chapter 7 (Table 7.4) it seemed that while Sue recognised Terry struggled, she did not appear to understand why this might occur and therefore the support he might need. Similarly, as described in the quote above, Sarah and Alex also appeared to have difficulty understanding why Ray might resist engaging in activities. Consequently, it appeared that these family members positioned the person with bvFTD as the problem, as suggested in Sarah and Alex's narrative above. In these circumstances, families appeared to use coping processes such as controlling and distancing, as described in previous sections (p251-9) in this chapter. Nevertheless, positioning the person as the problem, controlling and distancing appeared to add to difficulties within relationships as the person's attempts to support their own wellbeing appeared to be misconstrued as obstructive and hurtful as in the quote from Sarah and Alex above.

8.6 Chapter Summary

Awareness and understanding of the changes

All seven families contributed to the coping processes described in this theme. In two families, receiving a diagnosis of bvFTD enabled them to work together, develop their understanding and respond to the changes taking place. Accepting the diagnosis, learning about bvFTD and placing themselves in the shoes of the person with dementia underpinned the development of coping processes. These families engaged in learning from knowledgeable others to support them, including professionals, peers and others in order to developing their strategies. Collaboration included the person with bvFTD and also involved accepting that family members may have different levels of awareness and understanding. One couple described a similar approach to these two families although this collaboration did not extend to wider family.

Three of the families appeared to struggle to move from awareness to understanding and seemed to position the person with bvFTD as the problem. Similarly family members who were out of step with close family members in regard to their awareness were also positioned in this way. Although some shifts in positioning were seen over the duration of the research, it nevertheless appeared that avoidance and achieving a distance were used as a means of coping with the person with bvFTD and family members who were out of step in their awareness. Additionally, it appeared that conflictual communication arose. A feature of these family relationships appeared to be a lack of collaboration and poor affective and information based communication. Relationships with professionals and others also appeared to be poor.

We’re not the same anymore / I’m not the same anymore

The consequences of bvFTD involved an increasing level of dependence on those in closest contact with the person with dementia as the social and cognitive skills associated with living an independent life and engaging fully in relationships became challenged. In keeping with the coping processes described in the previous section, three of the partners appeared

to use acceptance and adaptation to respond to the changes. The coping processes appeared to involved ‘holding’ the person with bvFTD and continuing to support them to engage in everyday life while adapting and compensating for the difficulties they experienced over the duration of the research. These families appeared to strive to ensure that the person with bvFTD was not diminished by these coping processes.

One partner chose to resist and fight the changes brought about by bvFTD. She accepted the diagnosis and used similar strategies to those involved in acceptance and adaptation, however these were designed to support and maintain the person with bvFTD as they were for as long as possible. In order to achieve this she worked in collaboration with her family and knowledgeable others. Adaptation of coping processes occurred with new changes. However, by the third time point, it appeared that there were considerable emotional costs to engaging in this strategy.

Two families who positioned the person with bvFTD as the problem sought to achieve distance from them by engaging in care management and involving others in the person’s care. However, this wasn’t entirely successful in relieving direct caregiving responsibilities and other stressors were apparent, including managing the work of the carers and being unable to escape the persons’ care needs. Finally one partner appeared to feel stuck with the difficulties they experienced as a consequence of their partner’s diagnosis. They found it difficult to develop successful coping processes and seemed to find the changes difficult to bear throughout the duration of the research.

In this context partners and adult daughters were challenged to manage the personal costs associated with taking responsibility for the person with bvFTD, involving grief and loss at the changes and/ or the impact on their health and wellbeing. Some were able to acknowledge their grief and seek psychological support to address it. Furthermore, they also appeared to seek support through their relationships with others including friends, family and peers. Additional coping processes developed included taking time out, making realistic choices about what is possible and achievable and self-care. Some however appeared to take considerably longer to acknowledge their own needs including their grief. Consequently, accessing psychological

support and other self-care strategies appeared to occur at a much later point in the research, or not at all.

Managing everyday life

The coping processes used by families to manage everyday life appeared to be underpinned by the extent to which families were able to collaborate, communicate, address conflict, adapt and be cohesive. Families' coping responses to managing the impact of bvFTD on relationships and on everyday activities of living involved either enabling and facilitating; distancing, controlling and managing or avoiding and reacting.

The coping process of enabling and facilitating involved the primary family caregiver taking a lead role in engaging with and supporting the whole family to understand and work together in order to address the consequences of bvFTD for relationships and for everyday life. Two families appeared to work together to achieve this. The coping processes they utilised included scaffolding which involved planning and preparation, anticipating difficulties, embedding routine and structure and addressing safety. Other processes involved finding ways of maintaining an enjoyable life. One family also supported conversations about the emotional impact of bvFTD. While one of the other families did not experience collaboration with wider family, as a couple, they worked together to implement the coping processes described above.

The coping process of distancing, managing and controlling appeared to be connected with positioning the person with bvFTD as the problem. As described previously, two of the families sought to maintain a distance from the person with bvFTD. Where contact was required, both families utilised coping processes involving holding to the bare minimum of care needed and engaging in controlling responses designed to keep person in check. They also sought to control the actions of care staff involved in supporting the person with bvFTD. In one family, it appeared that control was used less over the duration of the research, however they continued to seek to achieve a distance from the person with bvFTD.

Finally, one family appeared to use avoidance and reacting as coping processes. The partner of the person with bvFTD appeared to find it difficult to adjust to the changes and the consequences of these changes for their relationship. While awareness increased, coping processes largely involved finding ways to enjoy life and reacting to or avoiding difficult situations. These coping processes had limited success as the partner struggled to adjust to the challenges associated with bvFTD.

Being me in the context of bvFTD

Five people living with bvFTD who participated in the research informed this theme. Coping processes associated with this challenge occurred across all three time points and involved strategies to maintain self employed by the person with bvFTD as well as strategies to maintain wellbeing. In order to maintain self, two persons with bvFTD acknowledged changes but continued to engage in activities and roles which supported self-concept. These included grand parenting and occupational activities. These activities were supported by their family members. One person sought to deny the changes that were taking place and emphasised that they were still the same person they had always been. While family members held an entirely different perspective, the person with bvFTD appeared steadfast in their belief that they had not changed. Two persons with bvFTD appeared to hold a tenuous self-concept which was influenced by concerns about stigma and the negative perceptions of others. Both were concerned about the way that they were perceived by others, although over time they were able to disclose their diagnosis to others in their life. It appeared that the position of ‘I’m still me, still active and engaged with life’ also featured in their accounts over time. Both participants engaged in activities that reinforced self-hood, suggesting that they found ways to continue to enjoy life as they adjusted to the changes associated with bvFTD. Similarly there were occasions when other positions were evident in the accounts of two of the persons with bvFTD. Therefore while all five participants held to one dominant position, to a lesser extent other positions were also evident in their narratives. Maintaining wellbeing appeared to occur on a continuum from ‘supporting safety and security and holding them through to resisting and restricting and positioning, controlling

and distancing'. Two families worked together with the person with bvFTD to support safety and security through holding to routines, to familiar environments and familiar people. Family members engaged in scaffolding activities to support the wellbeing of the person with bvFTD in this context. Furthermore, they sought to understand the emotional world of the person with bvFTD and develop coping processes that enabled the person to feel safe and secure such as physical holding and nurturing.

In contrast two of the persons with bvFTD sought to retain control through restricting activities that caused them to feel distressed and in doing so, frequently acted independently of their family. Close family members appeared unable to understand the reasons for their actions and positioned the person with bvFTD as the problem. Thus relationships became further strained and conflicted.

Therefore, it appeared that the families' coping processes to address the challenges wrought by bvFTD occurred on a continuum of **Assimilating, adjusting, reconstructing --- Resisting, denying, being stuck.** Some families and individuals within families appeared to shift their position on the continuum as awareness and understanding increased and coping processes enabled them to find ways to maintain and/ or reconstruct family life and support wellbeing. Others appeared to find this more difficult, reflecting limited movement on the continuum in the context of a difficult relational history and/ or trouble in finding ways to adjust to the impact of bvFTD. It is with this in mind that the final results chapter considers the outcomes for family relationships of living with bvFTD.

Chapter Nine: relational outcomes associated with living with behavioural variant frontotemporal dementia: a changing we/ I --- an entrenched we / I

9.1 Introduction

In Chapter six, I presented a narrative analysis of the family relationships of each of the seven families that participated in this research. As indicated previously, while these family storylines reflect the uniqueness of each family, it is nevertheless possible to see that their relationships ranged on a continuum of **cohesive and connected to disconnected and distant**. In Chapter seven I discussed a grounded theory analysis of the four challenges that these families and individuals within these families faced in living with behavioural variant frontotemporal dementia (bvFTD).

I then described a grounded theory analysis of the coping processes utilised by families to address these challenges in Chapter eight. Families and individual family members appeared to develop coping processes which ranged on a continuum of assimilation, adaptation and adjustment, through to resisting the diagnosis and the changes associated with this.

In this final results chapter, I consider my interpretation of the data in regard to the relational outcomes for these families and individuals within these seven families using narrative analysis. My use of the term outcomes is not to imply that an end point is being described. Indeed due to the dynamic nature of relationships and the progressive nature of bvFTD, it is inevitable that changes over time will continue to occur. Therefore in this chapter, I seek to represent the changes in relationships from the perspective of the families and individuals family members that had occurred during the research. Thus this chapter reflects that narrative moment in time. Additionally, as a consequence of the dynamic nature of relationships, the distinction between outcomes and coping processes is inevitably blurred. Consequently, the outcomes described here can also be viewed as coping processes.

As described in the previous chapters, I felt that families and individuals within families varied on a continuum of being able to adapt and adjust to the changes through to those who struggled to or resisted the need to change. Consequently I identified a superordinate theme, **A changing we /I ---- an entrenched we / I.** A number of subthemes emerged and I have presented these in table 9.1:

Table 9.1: A changing we / I ----- An entrenched we / I	
Relational outcomes for close family members including the person with bvFTD	• A changing we, stronger in a different way • Losing we, but still connected • Losing you so losing we, together but separate • There is no we, just getting through it
Relational outcomes for partners, adult daughters and their partners: the need for a changing I	• Becoming a new I, • An entrenched I
Relational outcomes for wider family members	• Closer together • Conflicted • Losing 'we'

Drawing upon the results presented in the previous 2 chapters, I begin by summarising the impact of bvFTD on the capacity of the person living with dementia for relational functioning given the changes to executive functioning and social cognition.

I then discuss my interpretation of the consequences of bvFTD for close family relationships (between partners and between adult daughters and their parents), considering how the relationship between the person with bvFTD and their partner or daughter and her partner was affected. Following this, I consider the relational outcomes for partners and adult daughters and their partners as individuals. Finally, I explore the consequences for wider family relationships, considering how relationships between the person with bvFTD,

their close family members and wider family have been affected for the whole family and for individuals within the family.

9.2 The impact of bvFTD

As has previously been described, bvFTD impacted upon a range of functions of those affected, including features of social cognition such as empathy, interpersonal relating and perspective taking. Furthermore, executive functions, including planning, initiating, monitoring and stopping behaviour and impulse control were also affected. Finally, bvFTD also impacted on processing and sense making, judgement and decision making. Consequently, these complex changes created considerable challenges for the person with bvFTD in managing everyday life, resulting in increasing levels of dependence on others for wellbeing to be maintained. Reliance on others began before diagnosis, with some close family members describing the need to take responsibility and think for the person before changes were understood. Furthermore, it appeared that this reliance additionally involved emotional dependence as bvFTD compromised the person's ability to feel safe, secure and in control.

Awareness of these changes and their impact was variable in the people living with bvFTD. While some had awareness that changes were occurring, it was nevertheless evident that this awareness was not congruent with their family members. Although some of the people with bvFTD appeared to accept that their families may have a different perspective on the impact of the changes, others seemed much less aware of this. Furthermore, the participants with bvFTD did not appear able to engage fully with the emotional consequences of these changes for them or for their family.

Consequently, close family members seemed to suggest that the person was increasingly less able to share in completing the everyday work associated with family life. Furthermore characteristics of the person that were previously valued, such as empathy, reciprocity, care and sensitivity to others were also perceived to have changed. It therefore seemed that bvFTD had a profound impact on the lives of the person with dementia and their family.

9.3 Relational Outcomes for Close Family Relationships

A range of outcomes were evident for couples and for adult children and their parents. These were:

- A changing we, stronger in a different way
- Losing we, but still connected
- Losing you so losing we, together but separate
- There is no we, just getting through it

These are now discussed.

A changing we: stronger in a different way

As I described in chapter eight, two couples appeared to accept and adapt to the changes in the person with bvFTD. Both couples appeared to collaborate to address the changes that had occurred, involving the need to change their relationship from one in which reciprocity and shared decision making featured, to one in which partners increasingly took responsibility to support the wellbeing of the person with bvFTD as well as managing everyday life (c.f. chapter 8 p.214-6). These changes began before diagnosis (c.f. chapter 7, page 139-41). Therefore even at time point one, Mollie and Anthony described needing to adapt:

Anthony *That's how it is. We're both reasonably good at coping, so you've got to adapt.*

Mollie *We've adapted – that's a good word, yeah. [T1]*

Similarly, Melinda and Bert also described a process of acceptance of the changes, although Bert contributed less to these discussions than Anthony. For both couples, this acceptance continued throughout their involvement in the research:

Bert *You can't do anything about it at the end of the day. It just becomes part of you, doesn't it.*

Melinda *I think once you accept that this is part of you and once everybody else accepts, well, this is a learning experience, it's a new way. […] I think that's when it becomes a lot*

easier. You know, I think it's just saying, well, you can't change it, it's learning to cope with it […] [T2]

Consequently, both couples recognised the impact of these changes on their relationship over time, although Mollie and Anthony were more explicit in acknowledging Anthony's increasing dependence on Mollie (table 9.2):

Table 9.2: the outcomes of bvFTD for close relationships

Anthony	*I'm dependent on you now and that's hard to accept.*
Mollie	*This is what he keeps saying to me. From the time we got the diagnosis ((Anthony)) says… I think he became frightened because "I don't know what I'd do without you" this is what he says, "I couldn't manage without you" I'm his…*
Anthony	*Memory bank.*
Mollie	*He calls me his memory bank. Anything that we're doing or anywhere we're going he relies on me. [T1]*
Anthony	*And that was the biggest thing really, was confidence and aggression as well. That was the other thing that we tended to get very aggressive with other boaters, the ones who like watching paint dry coming through […]*
Jenny	*So was it like that this time then?*
Anthony	*No. Taking the anti-depressants has calmed our aggression down a lot.*
Jenny	*Okay. And has that impacted on other parts of your life too?*
Anthony	*Yes.*
Jenny	*Yeah. In what way?*
Anthony	*Nothing specific. Just generally*
Jenny	*Okay. Is that something you've noticed?*
Mollie	*Yeah. I find that when we were away in May, on the boat, that Anthony was looking more to me for sort of, instruction.*
Anthony	*Instead of taking the lead I was just...*
Mollie	*You were looking for instruction weren't you.*
Anthony	*I was the crew and you were the captain.*
Mollie	*Yeah ((laughs)). I was the captain […].*
Anthony	*A role reversal.*
Mollie	*We didn't mind, did we, love. As long as we get there. [T3]*

As can be seen in these quotes, Mollie and Anthony appeared to have adjusted their ways of relating and roles within the relationship to adapt to the changes in Anthony and found ways to continue to enjoy life together. Adjustment was a process that occurred over time. Initially they had sold their boat because Anthony had become less confident and more dependent and Mollie had concerns about his safety. However by time point three they had adapted their ways of being to incorporate these changes in their relationship and had found a way to continue with their pastime. Subsequently both Anthony and Mollie commented that they had become stronger together as a consequence of these changes, even though this was different to the way they had envisaged being before his diagnosis:

Anthony *The important thing [is] that we work together as a team. We're not two separate people.*

Mollie *Yeah. He still keeps me in my place. He keeps me, not down sort of thing, but... How can I put it? You're a good influence, aren't you. [T3]*

Similarly, Melinda and Bert's narrative indicated that they sought to find a way to maintain the strong bonds that had underpinned their relationship. For example, they reaffirmed their commitment to each other by renewing their marital vows. Although they had intended to do this on their 50th wedding anniversary it was brought forward because Melinda had recognised Bert's concern that she wouldn't stay with him (table 9.3):

Table 9.3: finding ways of continuing to be strong together

Jenny *No. So tell me about this wedding, your renewal of your vows.*

Melinda *It was a good wasn't it. It really was good.*

Bert *Yeah,*

Melinda *It was a really brilliant memory, wasn't it.*

Bert *I've never met people like that before. I only ever met the vicar. But we went there and they showed us while he was talking about the history of the church and all that lot.*

Melinda *And the family were just so... It went from this quiet little thing into a bigger event. But it was really nice, […] And you're a lot better in yourself now. Because you said now you know that I'm not going*

	to disappear.
[…]	
Jenny	*So how do you feel your relationship is now?*
Melinda	*It's a lot better, isn't it.*
Bert	*Yeah, yeah [T2]*

Melinda also described working together with their children to find ways of supporting Bert and enabling him to be a part of their lives together. In this context, both Bert and Anthony appeared to accept that they had changed and largely trusted that their partners were acting in their best interests.

It therefore appeared that these couples were able to adapt to the changes and find ways continue to have meaningful lives together albeit in a different form to their prior relationship. Nonetheless, as described in chapters seven and eight, the impact of bvFTD resulted in a shift in relational roles which had consequences for the partners of the person with bvFTD. Both couples were interviewed together and largely maintained their narrative of acceptance and adaptation throughout the research. However there were times when Mollie and Melinda struggled with or chose not answer questions that were directed at how they had experienced the changes. Often this was in their non-verbal reactions, or outside of the interview. As referred to in the interview context, Melinda often alluded to her difficulties in this way. Consequently while it was important to them to present this united front, they nevertheless struggled with the changes to their relationship and it's meaning for their lives. This is addressed under the subtheme of a changing I later in this chapter.

Losing we but still connected

One partner and one couple contributed to this subtheme, but their narratives are significantly different so are presented separately. Phil Horton's narrative also contributed to the theme of acceptance and adaptation described previously in chapter 8 (p.216-7). However his experience of the marital relationship was also fundamentally influenced by the significant changes that had occurred in his wife Penny's wellbeing immediately prior to his involvement in the research. Phil explained that he had needed to place Penny into a care setting due to her significant needs. Consequently,

although Phil had accepted and adapted to the changes in Penny (c.f. p.217 chapter 8), her increasing difficulties and the recent transition into care had brought further challenges for him.

For example, Phil suggested that he was losing their togetherness now as Penny no longer recognised who he was at times:

> *Phil* *Up until two weeks ago I think she still recognised me, but on Tuesday this week I went to the hospital and she screamed the place down and she didn't want anybody in the room. And although she keeps asking for Phil and Leanne, which is my daughter, when I say "Look. It is Phil." "No it's not." Then she'll scream. But horrendous screams and her face all shaking (tone quiet, emotional). [T1]*

He seemed to find this change very difficult to bear and subsequently described his struggle to come to terms with the decision that he had made to place her in care. This struggle became more problematic for him because the care placement failed and she was admitted to a mental health unit where he perceived a lack of support and understanding for Penny or for their relationship as husband and wife:

> *Phil* *I mean, even now, my wife's in the hospital. She's supposed to be in a leading psychiatric hospital and you find that some people are sympathetic to the situation, I'm talking about hospital people and some people just couldn't give a [****] really. […] they have no understanding of how it affects, for example, my wife being seriously ill and how it affects me. They have no clue. They're very standoffish when it comes to talking about it. [T1]*

Therefore, the transition into care and Penny's deteriorating wellbeing caused Phil to feel he was losing her and their relationship. While she subsequently moved to a new care home where he felt the care was better, Phil nevertheless continued to struggle with his decision to place her in a care home. At the second time point, he seemed to experience regret and guilt about the decision and wished that he could bring her home (table 9.4):

Table 9.4: Maybe I should have tried harder	
Phil	*Oh yeah that's changed. I mean she's definitely deteriorated both mentally and physically. [pause]*
Jenny	*How has that affected you?*
Phil	*Well badly really. I mean ((sighs)) the problem I have is seeing her deteriorate, you know, I come home and think, 'Well maybe she shouldn't have gone into the hospital. Maybe I shouldn't have let her go into the care home. Maybe I should have tried harder to keep her at home,' it's a struggle to come to terms with that situation and sometimes I'll be lying awake thinking, 'Well what shall I do?' […] but my concern is that I don't want her to…she's ill, she's going to be suffering anyway but I don't want her to be suffering because she's outside of her comfort zone, if you know what I'm saying, her home environment.* *There'll come a time, I haven't done it yet, there'll come a time when I'll go and put some pictures on the wall and make the room a bit more amenable to her. I keep promising to do it. And I guess eventually I'm going to have to do it. But there's been a couple of times when I've thought that Penny was fading away and she might not be around if you know what I'm saying. [T2]*

It also appeared that he felt he might actually lose her as her health had deteriorated so significantly. Consequently, he sought to remain strongly connected to Penny and felt the need to visit every day, even though he acknowledged that this was very difficult for him. Furthermore he suggested that he resisted making her room homely and familiar. It is conceivable that his resistance to this was a feature of his difficulty in accepting the permanence of her placement as well as being related to her declining health. By the third time point, it appeared that Penny's wellbeing had stabilised to some degree. Phil seemed more accepting of the situation and remained connected to her through less frequent but regular visits which involved caring for her as well as monitoring and advocating for the care she needed. Nevertheless the changes in Penny, including her lack of recognition of him had caused Phil to feel that their relationship had fundamentally altered. At time point one he had recognised how lonely he felt and described needing someone to share his life with, although he didn't feel it was possible for him. By time point three he had embarked on a new relationship, although he still expressed his attachment to Penny (table 9.5):

Table 9.5: a new relationship	
Phil	*If I've got to make a new life for myself that gives me the opportunity whereas where I was before doesn't, you know.*
Jenny	*What does making a new life mean for you?*
Phil	*[…] So for me it's another relationship basically.*
Jenny	*Yeah.*
Phil	*That's what it will be and where it will go. I'll probably never end up sort of feeling the same way about anybody else as I've felt about Penny and as I still feel about Penny but nevertheless for me it has to be that kind of thing. I'm not…I can live on my own if I want to but it wouldn't be what I'd choose to do. No matter how loyal I want to be to Penny I'm in limbo really but by the same token I've just got to get on with it and make the best of what I've got, what I've got because I'm getting older by the day, you know and so that's it really. If that makes any sense to you.*
Jenny	*Yes it does. So you've got a lady friend?*
Phil	*Yeah who has been very supportive, very helpful, understands the circumstances and the situation, isn't jealous and spiteful of the situation, understands where I am, understands where I'm coming from and understands the situation with Penny and that Penny will always be the priority. [T3]*

Kate and Alistair Perrin also contributed to this theme. As has been described previously, Kate and Alistair were a strongly connected couple who valued their time together and each other's company as well as having identified family as central to their lives (c.f. chapter 6). Consistent with her previous role in the relationship, Kate was the driving force behind the decision to resist the changes brought about by bvFTD, using resources that Kate and to some degree their family were familiar with because of their previous experience (chapter 8 p.217-9). However as indicated in chapter 8, it appeared that while Kate remained strong in implementing and enabling this approach, it nevertheless had emotional consequences for them both. Kate's tone of voice appeared tremulous and quieter when discussing the changes that were occurring and the impact these had on their relationship. For example, Kate acknowledged at time point one that she didn't want to face the changes (table 9.6):

Table 9.6: We don't want to face the changes	
Kate	*We said last night, because we had a long talk about it last night, in between dances, that it was the whole... the realisation when I do bring him up on that, you've got to do this, you've got to start, put the effort in, I'm nagging him. To him the scary thing was realising how the disease, how the illness is...*
Alistair	*Hitting.*
Kate	*Yes. How it is actually progressing, because we keep thinking, no, no, no, we're not declining, it's not going any further. But the reality is we are and that's what we're not facing and we don't want to face it. So what we're doing is trying... and that's... that's happening.*
Alistair	*I'm trying to sort of say well that's how I was, this is how I am now, how much has changed. Trying to collate the two and that is the frightening scary part. You think, well I used to be able to do that, why can't I do that now. I don't feel any different in myself,[…] [T1]*

Similarly Alistair suggested that he found the changes 'scary', particularly when Kate pointed out differences in functioning that he had not been aware of himself. There was a significant difference in their discussion of this issue. It seemed that the focus of Alistair's narrative appeared to be on how he had changed. Conversely, Kate's use of 'we' may in part be indicative of her desire not to face the changes in their relationship wrought by the changes in Alistair. At time point one; Alistair described the changes to their relationship as more like brother and sister:

Alistair *Yes. Yes, no, we're... relationship with each other is about... it's more... it's not so much husband and wife these days, is it?*

Kate *No.*

Alistair *No. Brother/sister/friend. [T1]*

However, there seemed to be a lack of emotionality in his discussion of this, he didn't appear to recognise the emotional consequences of this change for Kate or for himself and seemed not to have noticed her distress when he said this (c.f. Table 7.18). By time point three, Kate explained that she felt she was mothering Alistair (table 9.7):

Table 9.7: Changing from brother/ sister to parent/ child	
Kate	*I think it's more like…I tend to be more mothering, yeah more mothering. It's because we went through like the brother and sister bit, Alistair was still my friend, I could still confide and talk to but because there's no empathy there isn't that same sharing of jokes, of information and because so much more responsibility is mine now for simple decisions like the car, the fence, all of it tends to be mine, I feel more as if I'm mothering than I am…*
Alistair	*Yeah the car, the fence.*
Kate	*When anything happens it's down to me to sort or me to organise or…*
Alistair	*It's "Kate do you want this…this is my idea what I thought does it match with you? No I thought it this way." So I haven't got the confidence to go ahead and do something straightaway I need that reassurance that I'm doing it properly.*
Kate	*But it's about everything though, it's about choosing clothes it's about…and everything stops with me [T3]*

And as this quote suggests, these changes resulted in the loss of many of the valued aspects of their relationship. Consequently Kate felt that she was losing 'we' while remaining connected to Alistair. His apparent lack of emotional engagement with the changes in their relationship further accentuated her sense of loss.

Alistair acknowledged that he was becoming increasingly reliant on Kate. He recognised that he was not functioning as he had previously; indeed he had suggested to Kate that he was not the husband he used to be:

> *Kate* *And you say things like…he says things that will upset me like, "I'm not a proper husband anymore because I just can't look after you." And he says things like, "It shouldn't be this way round, I should be there. It shouldn't be this way." And gets upset and then when he's saying that that's when I get upset. [T3]*

According to Kate, Alistair was previously particularly empathic in their relationship (c.f Chapter 6). While Alistair's reaction may have represented an emotional engagement with the changes, an alternative explanation is that Alistair was reacting to the level of emotion Kate expressed at these

changes. For example, Kate had previously suggested that her distress impacted negatively upon Alistair:

> *Kate* *So it isn't often I get really, really cross or really, really angry and since I upset Alistair so much a few months ago by being very angry he just said to me "Please stop being angry." I said "I can't help it." He said "But I don't like it when you're angry." And I realised that I hadn't vented my anger anywhere and I was actually taking it out on him. [T2]*

Therefore in the context of the emotional dependence he had on Kate (c.f. chapter 7 p.176-7), the distress he expressed at the changes may reflect his need to feel safe and secure which was strongly located in Kate. Thus these changes had considerable consequences for their emotional wellbeing and their relationship.

Losing you, so losing we; together but separate

The Lewin family (Ray, Sarah and Alex) and the Stuart couple (Terry and Sue) contributed to this subtheme. Both Sarah and Sue described previously positive relationships with the person with bvFTD. However, neither Ray nor Terry contributed significantly to discussions about the quality of their relationships prior to the onset of bvFTD (c.f. chapter 6), although Terry appeared to agree with Sue's narrative. Sarah described her relationship with Ray as having been very important to her, as a child and again after she returned home in 2000 (chapter 6). Similarly Sue reflected upon the importance of her life with Terry for her, reinforcing the reciprocity and care for each other that she perceived had been fundamental to her relationship with him (chapter 8 p.221-3).

As has been discussed in chapters 7 and 8, Sarah and Sue found it difficult to shift from awareness to understanding. Furthermore, when talking about the difficulties they experienced, their tone of voice often reflected frustration and anger with the person with bvFTD. Consequently it seemed that both Terry and Ray were positioned as the problem and their behaviour interpreted as deliberate. Indeed Sarah suggested that everything Ray had previously been to her had now changed. She and Alex also suggested that

he could control what he was doing if he chose to (c.f. chapter 8, p208-9). Ray's lack of awareness of his difficulties further compounded their frustration with him. Sue also appeared to blame Terry for his difficulties, which were the cause of frequent conflict in their relationship (c.f. chapter 8, p209-10). By time point three, Sue and Sarah had some appreciation of the difficulties inherent in bvFTD and why they might be occurring and their tone of voice appeared to have softened when discussing the person's behaviour. However, this did not impact significantly on their coping processes.

Furthermore, it seemed that their relationships with the person with bvFTD had fundamentally altered. Although neither Sue nor Sarah openly discussed feelings about the changing relationship in depth, it nevertheless appeared that they experienced grief and anger. For example Sue reflected on the change in affection within her relationship with Terry (table 9.8):

Table 9.8: Losing you so losing we

Sue	*I'll tell you what I do feel, Jenny, I just feel that it would be nice to have a bit of affection, so he'd do something for me and think, 'Oh that's nice, Terry, that's a nice thought,' or he'd say, 'We'll do this.' It's always I've got to say it. Like the other day, I said, 'We'll have a bit of lunch on my birthday,' and he said, 'Oh that's a good idea,' but he wouldn't think of that.*
Jenny	*And that sort of links to what you were saying about not having that compassion anymore?*
Terry	*Yeah, that piece is missing out of the jigsaw puzzle. I can't help that.*
Sue	*'Oh it's Sue's birthday, I've got to organise something for her birthday,' I don't get anything like that, nothing, not even a cup of tea in bed. The only time he makes me a drink, I made him start doing it and that's in the afternoon, half past three.*
Terry	*'Here's a cup of tea.'*
Sue	*He makes me a drink, but it took him ages, he couldn't remember whether I had tea or coffee and I've had tea in the afternoon for 40 years! ((laughingly)) You see what I mean?*
Terry	*But that is part of the symptom, isn't it?*
Sue	*Yes. [T3]*

Sue seemed not to have understood the difficulties that would lead to the changes and she seemed to feel frustrated and angry with him and their situation as well as a sense of loss. Similarly she also commented on the

absence of the compassion and support that Terry had previously given her, something she relied on due to her disabilities. Even though Terry acknowledged the change, they were not able to collaborate to address these issues; indeed the couple were defensive with each other. Again this became apparent in the tone of their conversations when discussing issues of contention such as that described in chapter 8 (p.209-10). Furthermore Sue did not appear to address her grief and anger in other ways either as described previously in chapter eight (p.227-8). Consequently, it seemed that Sue and Terry experienced a sense of helplessness to influence changes they were experiencing in their relationship. For example Terry described having to accept the changes in a manner that suggested resignation to the impact of bvFTD (c.f. Table 7.20). Similarly, Sue had also become resigned to the way their relationship had changed and chose to not dwell on what might happen in the future by living life together in the present:

> *Sue* *I find that by not dwelling on the situation of what it is and what it might be, I just think well if it's going to happen, if you're going to end up just sitting there like a zombie or something, that's what it's going to be, but until I get to that stage we'll just keep on trying to be positive, trying to go out or to do something. [T3]*

Although as identified previously, despite attempts to be positive, Sue continued to find it difficult to tolerate Terry's behaviour at times, particularly when he was unable to help her (c.f. table 8.30) and this resulted in an ongoing presence of conflict in their relationship.

Sarah also struggled significantly with the changes in her father, although I felt that her grief and anger was more commonly reflected in her narrative about his behaviour change, such as his refusal to attend the christening of his grandchildren (c.f. Table 8.14). As with Sue and Terry, Sarah experienced conflict with her father as a consequence of these changes and ultimately described the need to use avoidance as a coping strategy (c.f. chapter 8 p.196-7). Therefore even though she and Alex were able to reflect

upon the losses Ray had experienced by time point three and valued his relationship with their children, they described that their relationship with him had become tense and stressful:

Jenny *Yeah. So how do you see your relationship with him, because clearly when I first met you, you were talking about how he was a very positive person in your life […] and that you were very close.*

Sarah *Very, very.*

Jenny *How would you see it now?*

Sarah *((laughs)) Um…*

Alex *I think it's just more fraught [with] him.*

Sarah *Strained. [T3]*

Alex also described a greater level of conflict between them, particularly as he felt Ray demanded more of them now than they were able to offer. While Ray largely appeared unaware of the changes in their relationship, at time point three he did acknowledge that they did not always get on together and that their priorities might not be the same as his:

Ray *So it's very different ways, oh it is I think it's very difficult but Sarah and I clash a bit. Very difficult I suppose because the kids to a certain extent have to come first. So the children tend to come…I don't say in front of me but they tend to be, if they're outside and there was somebody crying I think you'd have to wait. And that bit of waiting might not be too good to me but there you are. But otherwise I can't grumble. [T3]*

As with Terry and Sue, Sarah and Alex also experienced a sense of being powerless to influence their relationship with Ray. Consequently, they commonly coped by avoidance and distancing. Nevertheless, Sarah and Alex felt that this situation had caused them to try and work together as a team of two and by time point three they were actively seeking ways to care for themselves as a couple (Table 9.9):

Table 9.9: caring for ourselves	
Jenny	*You said you went out on a date night last night*
Sarah	*We did […] we've started, we went to the [restaurant] last week. And we went out last night. So we're just going to start taking ourselves out of the equation, I'm not saying it's going to happen…I think it's like once a month type of thing but we've got a wedding coming up to go to, evening reception and yeah it's something that we haven't done before and now that the kids are a little bit bigger and we've got a reliable babysitter which we've come across so hopefully we're just going to take…and build…*
Alex	*A bit of time out for ourselves.*
Sarah	*…yeah and build on that and also, you know, look to the future and think right I can't do it this time round but I think we're wanting to go on holiday and, you know, plan things more when dad goes into respite […] [T3]*

Furthermore, while they perceived that their relationship had fundamentally altered, they valued the relationship Ray had with their children. Indeed it seemed to be a means of maintaining a degree of connectedness with him and a reason for him to remain at home even though this was very difficult for them:

Alex *This has been my biggest wish since we've had the two little ones is he stays around long enough that they can have a proper memory of Granddad.*

Sarah *Yeah.*

Alex *That's my biggest wish. I just hope that he can cling on as far and as long as he can, another ten years, whatever, but just so the kids have got a proper memory of Granddad not just me and Sarah saying, "He absolutely doted on the pair of you."[T2]*

Both of these close families struggled to assimilate the diagnosis and the resulting changes. The nature of the changes and the meaning of them resulted in a sense of losing the person as they had always been and therefore the valued characteristics of their relationship together. Both families felt powerless to moderate the impact on their relationship with the person with bvFTD and seemed resigned to the changes. Furthermore as adjustment to the emotional consequences of bvFTD for their relationship

was difficult for these close family members, conflict and/ or avoidance commonly arose in their interactions with the person with bvFTD.

Nevertheless, Sarah and Alex were able to seek ways to care for themselves and to find some meaning in their relationship with Ray through his relationship with their children. Similarly, Sue and Terry sought ways to enjoy life together for as long as they can.

In this context Ray and Terry appeared to act independently of their close family members in seeking to maintain their self-concept and wellbeing. For example as described previously, Terry sought to defend himself against Sue's apparent criticism of him by challenging her perspective. Similarly Sarah and Alex suggested that Ray engaged in active resistance and in attempts to control them:

Sarah *And he goes on about, "Oh when I was younger I used to do this and I used to do that," and whatever and, "Life has changed and these youngsters don't do it," and whatever, well I think he's only on about us but then if we go and say, "Oh we're going out," or we've got this on or we've got that on. […] "Why?" and he doesn't like it.*

Alex *So if we'd got somewhere to go he wouldn't be happy.*

Sarah *If we've got a party to go to then no he doesn't… "Where are you going? How long are you going to be?"*

Alex *That's right and if that's the case just when we're about to go he'll want the loo.*

Sarah *Oh yes. […]*

Alex *That's clued up that is, that's not…it's almost like, "But I know how I can keep you here a bit longer." [T2]*

It is possible that Ray would hold a different perspective about his intentions. Nevertheless, he did appear to resist their attempts to engage him in family activities such as the christening of his grandchildren. Throughout the research he emphasised his desire to remain at home, asserting that the world had changed for the worst so he wasn't missing anything:

Ray *So I said no I'm quite happy to sit in my chair and watch a bit of racing. […] But things go by now and things go by as far as I'm concerned. But all I do know Jenny is that people who come to see me […] They say, "I'll tell you something my boy you're not missing anything outside that but what you've got." Because there is bugger all going on apparently. People have changed, it's all changed. Life has changed. And they said, "You are not missing this and that." And I said, "Well that's all right." [T2]*

Thus while these families remained connected, bvFTD had brought about fundamental changes to relationships which cause those closest to the person with bvFTD to feel that they were losing 'we'. This also resulted in family members acting independently of each other, including the person with bvFTD.

There is no we, just getting through it

In contrast to the six other families, the prior relationship between Pamela and Jonathan Hugh and her mother Elizabeth had been described as difficult and characterised by distance, disconnectedness and a lack of affection (c.f. chapter 6). While initially care had willingly been provided as a consequence of the death of Elizabeth's husband, the nature of the difficulties experienced as a consequence of bvFTD had cause them to come close, disrupting the boundaries that they appeared to have created to maintain a tolerable distance, resulting in conflict.

Significant risk taking and an apparent lack of awareness resulted in Pamela and Jonathan taking control which continued throughout the duration of the research in order to minimise risk and ensure her needs were met. For example they described having to try and stop local businesses from giving Elizabeth items as she wouldn't be able to pay for them (table 9.10):

Table 9.10, taking control to minimise risks	
Pamela	*[…] And that was the difficulty that we had because my mother was going in all of the local shops and asking to take things home and she'd pay them later and this sort of thing and I literally had to go in every shop and say, "My mum's ill please do not let her have anything because you won't be paid because she hasn't got the money to pay you," and some people were really horrible to me. And they just didn't comprehend. I mean there's one shop in the village that I will never, ever step foot in again because of the way they treated me and all I was trying to do was protect them from losing money basically. [T1]*

However, it appeared that they felt she resented this control, did not accept that there was a need for their actions and blamed them for restricting her:

Pamela *Well what she sees is that I say no.*

Jonathan *That's right yeah. […] That's why she doesn't really want Pamela to know anything that she's doing. She'll say to the carers, "Don't tell my daughter." And they'll tell us ((laughingly)) she said, "Don't tell." Of course but.*

Pamela *((laughs))*

Jonathan *But we know she does that because she knows there's a risk that Pamela will say no. [T3]*

As has been described in chapter seven and eight, this increased contact caused further damage to an already difficult relationship. As with Sarah and Sue, their tone of voice suggested that they were angry and frustrated when discussing Elizabeth. It seemed therefore that Pamela and Jonathan positioned Elizabeth as the problem and largely perceived the impact of bvFTD to have exaggerated existing personality characteristics which were not valued by them, including being self-serving. By time point three, Pamela and Jonathan expressed the view that they no longer wanted a relationship with Elizabeth. Indeed Pamela stated that she felt she hadn't got a relationship with her mother:

Jenny *Mm so how do you think your relationship with your Mum has been affected?*

Pamela *I haven't got one. It sounds awful but I don't want to see her, I don't want to do anything for her, […][T3]*

Furthermore she suggested that she wished her mother would die. It seemed as though this was the only way that they felt they would be free of their involvement with her. Consequently, as described in chapters seven and eight, they sought to minimise their contact with her as much as possible.

The difficulties they experienced in their caregiving role for Elizabeth had significant consequences for their relationship as a couple (Table 9.11):

Table 9.11: The consequences for their relationship as a couple

Jonathan *Yeah and more than that you can't talk about it calmly. We couldn't talk about calmly could we?*
Pamela *No.*
Jonathan *We're always like rising and you might not think we're very calm but we're quite calm tonight ((laughs))*
Pamela *((laughs))*
Jonathan *Yeah if you'd come to see us two years ago you'd have probably been in the corner by now. You can feel it and I keep saying now, "Just calm down, calm down," because it's not worth it and we do we get very heated, or we did get very…even when I'd call a friend of mine, particularly who was involved in social work, a guy I've known since I was six years old and I found myself actually almost shouting down the phone at him ((laughingly)) as if it was his fault for the social service system and of course it's not obviously nothing to do with him but that's how it got us and we had to offload it somehow. [T1]*

As described in chapter 6 (research context) and above, at time point one Pamela and Jonathan experienced high levels of stress as a consequence of their caregiving. This impacted upon their relationship as a couple and as indicated above, the relationships they had with friends. Indeed they commented that it had taken over their lives and was the only thing they talked about. However by time point two, a health crisis had caused Jonathan and Pamela to re-evaluate their wellbeing individually and as a couple. Consequently, Pamela described the need to care for themselves and each other:

Pamela *And you just have to reassess what you do, don't you, on a day-to-day basis. And I think that Jonathan and I are being a bit more organised with everything in the house, because the house was getting in a right state. […] So it's been a bit like*

saying 'Oh well. If I'm not chasing round I've got more time here and I can organise things.' And that will make me feel a little bit better. […] So we have been trying to do a bit of nice things in between. […] So we are trying to have some time together rather than just to be bogged down with it. [T2]

It appeared that this also reinforced the use of distancing as a coping process in responding to Elizabeth as described in chapter 8. Indeed Pamela described avoiding contact as much as possible and focusing only on getting the basics of care done. However, it appeared that Pamela and Jonathan remained connected to Elizabeth through their caregiving role and felt that it was impossible to relinquish this contact completely:

Jonathan The power of attorney said, very gallantly, "Pamela needs support she can't do all this on her own," but there's no solution, there's nobody's come forward and said, "Okay we'll take this on and we'll…" you know, there is no solution,[…] [T3]

Consequently they seemed ultimately to become resigned to their caregiving role and believed that they would only be free of this after her death.

9.4 Relational outcomes for partners, adult daughters and their partners: the need for a changing I

As described earlier and in chapter 8, close family members experienced a significant shift in their relationship with the person with bvFTD. Many of the partners appeared to take on increased responsibility for the person with bvFTD, while experiencing a loss of many of the valued aspects of their relationship. Adult daughters also experienced changes in the relationship. A previously poor relationship seemed to give rise to conflict and a sense of entrapment for one adult daughter and her partner. In contrast, a previously positive relationship appeared to result in a significant sense of loss in the other adult daughter which in turn seemed to give rise to difficulties in adjusting to the changes in her father.

However, even where it was possible to negotiate a changing 'we' partners; adult daughters and their partners experienced challenges to their own sense of self resulting from the consequences of bvFTD for their relationships with the person with dementia. Coping processes involved accepting the need for a changing self, grieving the losses experienced and finding ways to care for themselves. Relational outcomes for these family members appeared to involve having 'a foot in both camps' that is finding a balance in supporting the person with bvFTD while addressing their own relational and individual needs. This is addressed under a continuum of: **Becoming a new I --- An entrenched I.** This continuum is now discussed.

Becoming a new I

Over the duration of the research, four partners (Phil, Kate, Melinda and Mollie) appeared to move towards developing a new self. This seemed to be a gradual process which involved, as described in Chapter eight, an acknowledgement that changes to relationships were taking place and that they needed to address their own wellbeing. Developing relationships with others, within and external to their families occurred as a consequence. The pace at which this transpired varied with these four partners and seemed to be influenced by the nature of the changes the person with bvFTD was experiencing, their readiness to address their grief and the availability of support from others.

For example as described earlier, Phil experienced a significant transition prior to becoming involved in the research as his wife Penny's increasing needs had necessitated a placement in long term care. As described above (p.289) Phil had initially described how lonely he felt. I also experienced a sense of loneliness and grief when visiting his house, an almost tangible sense of 'coldness' in the room (c.f. chapter 6, research context). Over the duration of his involvement in the research, it appeared that Phil engaged in a grieving process in which the changes in Penny were acknowledged following which he recognised his need to change.

Therefore at time point two, he had put his house up for sale:

Phil *I've come to the conclusion that probably I'm going to have to move house because every time I come in here it just feels like empty [T2]*

Furthermore by time point three, Phil described the motivation for moving home:

Jenny *You said that it was difficult to go into the old house when you got home?*

Phil *[…] Yeah absolutely. It just didn't feel right at all ever, from the day she moved out. Instead of getting better it got worse.*

Jenny *Mm.*

Phil *So from that point of view I'm better being here than I was there, you know... […]*

Jenny *Yeah so is that about making this your house?*

Phil *Well it's still our house whether I like it or not but the fact that she's never been in it and is never likely to be in it makes it easier for me to bring people back here.*

Jenny *Okay.*

Phil *If I've got to make a new life for myself that gives me the opportunity whereas where I was before doesn't, you know. [T3]*

Thus Phil was able to move towards developing a new life for himself, which included as indicated previously, developing a new relationship.

However the other three partners were at a different point in their lives with the person with bvFTD. All three people with bvFTD were living at home; additionally at the beginning of the research two had only recently been diagnosed. Consequently, a shift to developing a new self occurred in more subtle ways, reflecting the continued presence of the person with bvFTD in their lives and their considerable involvement in supporting that person. Furthermore it appeared to reflect a gradual process of assimilation of the diagnosis and its consequences for them. For example at time point three,

Mollie seemed to recognise that it had taken a long time to adjust and adapt to the changes in their lives and their relationship together:

> *Mollie* *But I don't think its Anthony. I think it's more me. It's taken a long time to adjust, it really has. [T3]*

Similarly, Kate and Melinda appeared to experience a gradual and for Kate a lengthy period of assimilation, acceptance and adaptation as described previously (table 8.8 and 8.10). All three acknowledged the limits to their capacity to care and remain patient in the face of the changes in their relationship and the challenges associated with the level of care and support their partner needed. For example, Melinda referred to her frustration with Bert's behaviour at times:

> *Melinda* *I suppose I'm not a saint and sometimes I get very, very frustrated with it all [T2]*

Each of them suggested that they had therefore come to realise the need to care for themselves (table 9.12):

Table 9.12: I have to care for myself	
Melinda	*Because you do lose yourself in it all. It's recognising, yeah, you've got needs and to bring that forward.[T2]*
Mollie	*[…] I think it can if you're not careful pull you down, pull me down. [T2]*
Kate	*[…] So I thought, well I'll try anything because if I go to the doctor he'll say, "You're overworked, you're stressed, therefore the answer to stress is a pill," and I don't want to take anything. I don't want anything that is going to make me less clear than I am now. So there's no way I'm taking anything and I thought, if I'm not going to go to the doctor I've got to sort it myself. [T3]*

Furthermore, it also appeared that they recognised that they could become engulfed in caring for the person with dementia to the exclusion of their own needs. Indeed prior to time point three, Kate had been self-critical when describing that she couldn't influence the progression of bvFTD in Alistair:

Kate *so I just spend this time feeling that I'm a horrible wife and a crap person ((laughingly)) pretty much. So that is hard. [T1]*

Consequently, in table 9.12, her quote reflected a realisation that her emotional wellbeing was suffering and that she needed to address this. Melinda also described how easy it was to become exhausted; particularly given the changes they had experienced over the duration of the research including moving house and her need for an emergency hospital admission. Therefore she highlighted that time for herself was a necessity:

Melinda *It's a coping strategy. And Bert's also aware now that sometimes I have to, when life gets to me, I have to have time for myself, where before he hated that. [T1]*

Thus acknowledging and recognising their own needs appeared to involve meeting their needs for reciprocity and care through strengthening their relationships with others as well as those coping processes described in chapter eight. For two of the three partners this involved shifting allegiances within their existing relationships with family. As described previously for Kate and Melinda this resulted in stronger bonds with children and for Kate also with her parents (Table 9.13):

Table 9.13: shifting allegiances	
Kate	*And Liz is very good. She's very, very good about just letting me talk without making me feel guilty, or making me feel as though I'm burdening her. [T2]*
Rena	*[…] Phone rang and it was Katherine and she said "Mum, we're locked in the conservatory. The conservatory door won't unlock." And I said to her "Do you want us to come?" and she said "Oh, can you?" and then I said "Yeah, we're ready, we'll be there." [T3]*
Melinda	*Right. We'll talk, we'll phone and if something happens one of us will make sure that one of us gets in contact with that person. […]. And they've encouraged me by saying "It's alright to say that you get frustrated and you get angry. That is fine. When it gets too much, ring." And that's what I can do. I can ring and they'll come for a couple of hours and I'll get a couple of hours off.[T2]*

Therefore both Kate and Melinda strengthened existing relationships with family members and confided in them in order to address their needs for emotional and practical support as individuals, as well as managing their caregiving role. However, this did not appear to be without difficulty, as both Kate and Melinda had referred to the need to protect their children from the full consequences of the changes.

It seemed that investing in closer bonds with family was not possible for Mollie, given the difficult relationships she experienced with her children (c.f. chapter 8, p.211-2). Consequently her narrative seemed to suggest that she had re-engaged with and strengthened relationships with friends:

> *Mollie* *Well, I've started going out a little bit more with friends and meeting for coffee and things like that now. I've took on board what the doctor said and what specialist nurse said. "You've got to look after yourself." Because not only with Anthony, but I was also looking after Pete and his problems. And I've actually walked away from that. I've had to walk away from that for my own wellbeing. So, getting there, slowly. But Anthony's got to be my priority. But no, for instance, go over to the library once a month. We do a family history thing over there. And when you go over there you're sat talking to people and you're thinking on the normal day-to-day. Not having to remind that person they've got to do something, or they've got to... you know what I mean. Or go in for a coffee with friends in [city] and having a good old chinwag, a good old gossip ((laughs)). […] [T3]*

Furthermore, she also seemed to rely upon regular contact with the specialist nurse as her confidant, as well as making decisions about priorities and the limits to what she could do. Additionally all three partners had also described developing relationships with peers as a source of support (c.f. chapter 8 p.227).

An Entrenched I

One of the adult daughters, her partner and one of the partners (Pamela, Jonathan and Sue) appeared to be closer to an entrenched position on the continuum. These close family members shared a difficulty in moving from awareness to understanding, positioned the person with bvFTD as the problem and utilised coping processes including distancing, avoiding, rejecting and controlling. Furthermore they also shared a sense of helplessness in the face of the changes that had occurred in the person with bvFTD. Consequently they may not have recognised the need to change themselves and/or were unable to sustain changes that might be needed.

Pamela seemed to feel alone with the responsibility of caring for her mother. While Jonathan shared in some of the activity, Pamela suggested that she was largely responsible for her mother's care:

> *Pamela And my comment was, "Well there is nobody else to do it," and I think I feel now there isn't anybody, well Stan could do it but he's not capable. So therefore I suppose […] I feel as though I've been landed with that responsibility. [T1]*

Furthermore Pamela and Jonathan identified that caring for her mother had strained their relationship which may have further heightened this sense of aloneness:

> *Jonathan Well it became virtually the only topic of conversation, virtually the only thing that we talked about and it certainly hasn't helped the relationship between us. [T1]*

Jonathan also acknowledged that Pamela was the primary supporter as he was away for significant periods of time with his work. However, at time point two, it seemed that Jonathan and Pamela sought to strengthen their relationship and become closer. Pamela suggested that they were trying to take time for themselves as a couple:

> *Pamela So we are trying to have some time together rather than just to be bogged down with it. [T2]*

Nevertheless, at time point three the weight of responsibility for Elizabeth's care continued to be held by Pamela, as did her sense of helplessness. Indeed Jonathan reinforced that it was Pamela's responsibility to care for Elizabeth as her next of kin and further acknowledged that he was less involved:

> *Jonathan […] you know, there is no solution, unfortunately and I was saying this the other day there's no way out of it, Pamela's stuck with it because she's next of kin, her brother's no help. […] I'm the call answerer when I'm here really basically. I make a few calls but, you know, really there's no way of offloading what Pamela does [T3]*

It is possible that this was being enacted in the interviews as despite agreeing to participate in the research, Jonathan chose not to be present at time point two and left halfway through the time point three interview. Pamela additionally emphasised that support from her brother was not forthcoming:

> *Pamela No well he doesn't talk to me so we had a meeting, […] we were all saying that we all ought to be singing from the same hymn sheet in regard to payment of her care and how much care went in and he was asked specifically what do you think? And he said something like, "I can't think about anything but myself because I'm not well," so you're thinking well you're at a meeting, this is what we're discussing and you're saying that you can't even contribute to what we're actually talking about. […] [T3]*

It appeared that Pamela and Jonathan did share their experience to some degree and sought to find ways of strengthening their relationship. Nonetheless Pamela seemed to feel alone in her responsibility to care for her mother which was further heightened by the lack of support from her brother. Furthermore Jonathan also felt helpless to influence the situation:

> *Jenny No. How do you manage…*
> *Jonathan Me?*
> *Jenny … the impact, yeah?*

Jonathan Oh well I just, I'm rolling with it now really ((laughs)) it's not, you know, there's no light at the end of the tunnel as far as I'm concerned, she'll probably outlive me it's just there's nothing we can do. I feel absolutely powerless really to do anything we just make the best of a bad job. [T1]

Consequently, he limited his direct involvement with Elizabeth, thus acting independently of Pamela.

Sue Stuart also appeared to experience a sense of being alone with the challenges she faced. She rarely acknowledged the need to confide in her daughter or others. As described previously, her daughter Carole suggested that her mother was talking with her about the difficulties she experienced with Terry and that this involved exploring solutions to challenges she faced. However, by time point three any closeness that may have existed seemed to have ruptured (c.f. chapter 8, p.237-8). Consequently, while Sue acknowledged the difficulties she experienced at the changes in Terry, she did not appear able to find ways to support herself and address her own needs. Indeed it seemed that she did not recognise the need to change herself, rather she appeared to focus largely on positioning the problems in their lives with the changes in Terry's behaviour.

A risk associated with occupying an entrenched position appeared to be that of a decline in personal wellbeing. Many of the participants described personal costs to their caregiving, as described in chapter 8 (table 8.15), however it appeared that for some the realisation of these costs was a pivotal moment which stimulated action such as that described by Kate above (table 9.12 and p.305-7). However while Pamela experienced consequences to her health and wellbeing (c.f. table 8.15), she did not seem able to engage ongoing self-care strategies. Indeed, it appeared that Pamela was experiencing a loss of the person she felt herself to have been.

Pamela And the worse thing is I'm just a crabby old woman, that's how I feel, I'm just resentful and angry and I know that I am and I know whatever comes out of my mouth I'm thinking, oh you just sound awful! But it's like I can't even stop myself

because I feel as though I've been ground down to such an extent now that I don't know when my life is going to be normal again and the thought of another ten years with my mother as it is with no escape is just horrendous.[T3]

At the start of the research Pamela had already been supporting her mother for over 6 years; consequently this length of time may have contributed to her declining wellbeing. Nevertheless, while she acknowledged that the costs were too high, she did not appear to feel able to consider how to manage her situation before it further damaged her wellbeing. Nor did it seem that she had the support she needed to make such changes.

Sarah and Alex Lewin appeared to occupy the middle ground on this continuum. As described previously, they shared much in common with Pamela and Sue in regard to their difficulty in moving from awareness to understanding, in their positioning of her father as the problem and coping by distancing and controlling.

However, in contrast to Pamela and Sue, it appeared that they had support available to them and seemed able to make some changes to their situation. Thus while they were critical of Ray's sisters for their lack of support at time point one, by time point three, it appeared that they felt that as a family they had support from other family members and friends (Table 8.20). Additionally, while in some respects it appeared that Sarah and Alex were stuck in their attitudes towards Ray, they nevertheless appeared to move towards recognising the need to care for themselves. By time point two it appeared that the help they received from professionals enabled them to accept respite care and to have conversations about their own needs:

Sarah *[The specialist nurse] came the other day, well two days ago, […] He demonstrated his…*

Alex *Displeasure.*

Sarah *…displeasure that we were talking about something else other than him and we quickly turned it around that… but it's only [the nurse's] way, she's got to work with us as a family*

and so she's getting to know Alex, myself and Dad and yes the majority of her appointment is with Dad but she also does need to know what our needs are and what our interests are because we've got to have a balance as well in life.[T2]

By time point three it seemed that Sarah and Alex were able to engage more collaboratively as a couple to meet their own needs (c.f. p.296-7), which also included supporting each other to manage the difficulties they experienced with Ray:

Alex *But Sarah's started to listen to me a little bit more and coming away and walking away.*

Sarah *((laughs)) I do now, I've got to for my own sanity now.[T3]*

Thus, as in this example, they were able to recognise that they were able to care for themselves by working together.

9.5 Relational outcomes for wider family relationships

As has been described in chapters 7 and 8, wider family members also experienced significant challenges to relationships as a consequence of bvFTD. In the context of the superordinate theme **a changing we --- an entrenched we,** a number of subthemes for relational outcomes for wider family members emerged:

A changing we:

- Closer together

An entrenched we:

- Conflicted
- Disconnected
- Drifting apart

A changing we: closer together

As has previously been described, it appeared that the Perrin and Morris families sought to work together to address the challenges brought by

bvFTD, in the context of a prior family relationship that included cohesion, open communication, collaboration and conflict management.

Working together involved wider family members who were not living with the person with bvFTD and their partner. Thus in the Perrin family, their adult daughters and Kate's parents were significantly involved in Alistair and Kate's lives and in providing much needed support. Similarly, in the Morris family, Melinda described a longstanding connectedness with their 7 children and grandchildren. She subsequently discussed how they had come together to support Bert and to provide mutual assistance to manage the impact of bvFTD on their lives (c.f.chapter 8 p.232-3).

Melinda and Bert's children did not participate in the research consequently it is not possible to present their perspectives here. However from Melinda and Bert's perspective, they had moved closer together as a consequence of Bert's diagnosis. Being closer together involved reciprocal exchanges of support and assistance to address emotional needs (c.f. table 9.13), problem solve and meet practical needs:

> *Melinda* *We have had to put a clock in the garden though, because now he's got this fixation that he'll start and he'll just keep going 'til he drops. So we've put a clock in the garden now so we can say "Right, when it gets round there you come in, sit down, have a breather and a snooze. And then go back out." […] So they're very much onto it and they came up with the idea of the clock. […] And I think they've got a better understanding of it now and they're always looking for new ways of helping you, aren't they. Like photographs with names and things like that. [T2]*

Thus their children were actively engaged in managing the impact of bvFTD. Furthermore, as described in chapter eight (Table 8.18) and raised above (table 9.13) the emotional needs of wider family members were acknowledged and addressed as a part of this reciprocity.

Kate and Alistair's daughter Rachel and her parents Rena and Dave also participated in the research. As has been described previously, all three were

closely involved in their lives and as with the Morris family, this closeness reflected longstanding patterns of connectedness.

Coming closer together to support Alistair appeared to be positive in maintaining and strengthening relationships within the family. Indeed Alistair seemed to feel a sense of security and safety when with his family. For example he and Kate described that he was more comfortable when going out with Rena and Dave as it seemed that they also reinforced his sense of safety and security. Furthermore he also highlighted how Dave's support had become important in helping him to manage and be motivated:

Kate *So my dad's back round again driving things forward and…*

Alistair *Keeping me motivated.[T3]*

Similarly, when Kate was at work, Rachel often used to call in to see her father, because she knew he struggled with being alone at home:

Rachel *She doesn't like to leave him on his own for any length of time at all. So if she's going out for the evening I'll pop round and have a chat and stuff. I don't think he likes to be on his own either.[T3]*

And Alistair confirmed that knowing she was close by was helpful to him:

Alistair *If you're not there and she's there I know I can go round no matter what. [T3]*

However this closeness also brought challenges for them. For example, Rena and Dave described an increasing awareness of the impact of bvFTD on both Alistair and Kate (table 9.14):

Table 9.14: the impact of bvFTD on Alistair and Kate	
Rena	*[…] they have to take the motorhome down [to south of UK] […]So we're due to take it down on Saturday. So all four of us are going, so that we can come back all together. It's somewhere past Bristol we've got to go down, that way. So it was decided, because Alistair's not allowed to drive it any longer. So Katherine would drive it, but I would go with her because I would chat to her. And Dave and Alistair will go in our car. And then we'll all come back together and presumably we'll do the same when we go to collect it. But Katherine wanted me there because she wanted someone*

	to talk to because she said Alistair wouldn't. He wouldn't chat.
Dave	*Well, it's no surprise. I don't chat.*
Rena	*No, you don't. But Alistair always did, you see. And that motorhome's big for her to drive on her own. […] And a complete role reversal. Whereas Alistair always drove and the caravan was Alistair's thing and she just did catering and that sort of thing. Now of course, she's in charge of the driving and that sort of thing. So they've completely changed roles there. Which is, I think, in a way hard for him too. [T3]*

In this quote it appears that they are exposed to and recognising the change and the impact of the changes on both Kate and Alistair, in particular the role reversal and increasing reliance on them. While it is evident that they willingly gave of their support, they also appeared to experience distress and sadness when talking about these changes. It therefore seemed that this increased exposure was also challenging for them. Dave had acknowledged previously how difficult it was for him to face Alistair's diagnosis because of his fears that he might also develop dementia:

Jenny	*And have you looked for anything to tell you more about it?*
Dave	*To be quite honest no. but whether that is because I'm fearful of what will happen I don't know […] and quite often I'm wondering whether this is happening to me and I don't want to know to be quite honest it's as easy as that so that could be clouding the judgement as well.[T1]*

Rena also expressed concerns and in response to my question about the future, highlighted that she had fears for what will happen when Alistair was no longer able to work. She acknowledged that there were limits to the support that they could provide because of their age and were worried about the level of support that Alistair would need:

Jenny	*[…] How do you think Alistair and Katherine see the future?*
Rena	*I think Alistair sees it blackly and I think Katherine tries not to look. I think we're all holding our breath that he keeps his job, because that is going to be, if a time comes when he's at home, then we all have real problems. Dave and I are too old to take him on. And Katherine doesn't expect us to. But she*

is only fifty-three. She's got a few years that she's got to work. And financially she'll need to work. So what happens to Alistair? He doesn't like her not being there. He can cope if Dave's there, but he doesn't like her not being there. So how is that going to work? I think that's what scares us all. And there isn't an answer.[T3]

Furthermore, they were also worried about Kate and her wellbeing, recognising that she was increasingly relying on them and experiencing high levels of stress. Kate also appeared to be aware of her increased reliance on them and the challenges this created for their relationship (table 9.15):

Table 9.15: challenges for wider family relationships

Jenny	*You talked about your parents and that they only see certain things, how does that affect your relationship with them?*
Kate	*Most of the time I'm just very grateful for the fact of the support they give me, so it doesn't really, just occasionally I'll think "Oh, for God's sake." But then I realise that, the practical person in me realises that they can't help that, that it's not deliberate and it's not done to wind me up. It's just a lack of understanding. […] It means I'm not going to yell at my mother and say "How dare you do that?" and oh God, I don't want to fall, out with her and that's what would happen, because she would get upset and I can't let that happen. I can't let it happen for a whole host of reasons. But for Alistair as well. and, so no, it's its, you just deal with it you know. […] [T2]*

Thus as Kate appeared to suggest, having a greater reliance on them required that she was sensitive to their experience and needs. Additionally it also seemed to require her to actively manage possible sources of conflict because she and Alistair needed them.

The increased closeness also caused challenges for Rachel in her relationship with her Mum and Dad. Rachel was experiencing a transition in her own life during the research, as she got married and had plans to start a family. However, she had also acknowledged an increased reliance on them because of her experience of Asperger's at time point 1:

Rachel *because I'm a lot like him and I'm sure mum has told you, I've got Asperger's, so moving away and the thought of*

staying away for a long time, I didn't like. I realised that when you get to an adult you have to move away and you have to stand on your own two feet and all the rest of it. And I had Mike, so that was fine, but I didn't particularly like it. […] So, the fact that now it makes it easier for me to be [here], it then can rationalise it to everyone else, […] The main reason is that I'm more comfortable […] being here, the flat I'm in now is the home I've grown up in [T1]

At time point two she had also described being involved in caring for her Dad, as a consequence of conversations with her parents. Indeed she suggested that she would be supporting him once he finished work while she was at home with her baby. It is conceivable that these competing demands caused Rachel some dissonance, as she subsequently seemed upset that her sister was getting involved in caring for her father and had suggested that she would be less involved:

Rachel *My sister's made a couple of comments on the fact that she's going to be looking after him, or helping to look after him. She's said how she couldn't have another child because she'd need to help look after my dad and bits and pieces like that which I thought was funny because apart from very, very recently as in the last two or three months of me planning the wedding where I've been stressed the rest of the time, she doesn't really have that much to do with the family, if you see what I mean. She comes over for Sunday dinner and then goes and then that's it whereas I'm the one that pops in, in the evening, that…I'm not saying I'm looking…I'm helping at all really, although if my mum was to go out for the evening it would be me she would text to say, you know, "Just go and call and check on your dad tonight," or, "I've told your dad you're upstairs if he needs you," and things like that. Whereas she's said that she thinks it's going to be on her because Mike and I are now married that we're going to be off and not really helping with the whole family life like as a*

big unit instead of just a nuclear one. So that was quite hard for me to take because I thought, like my mum and I had been talking about the fact that I'd be the one to look after him […] So it was quite…and I just, you know, if it didn't happen then it wasn't the end of the world, it's not like I'm relying on the fact that I'm going to be helping looking after my dad but or will have my dad to help me but it just kind of made sense. So the fact that my sister thinks she's putting her life on hold a bit [T2]

However it seemed that by time point three, Rachel had shifted from this perspective and suggested that she and her parents were close but not over-involved:

Rachel *No I just think it's the fact that I've got my own life and they've got theirs I know if my mum did need something she could ask and she doesn't want to be imposing on us and I don't want to be interfering on them so sort of leave it if either one wants to then we can but it's not forced. [T3]*

This coincided with a significant life change for her in that she was nearing the end of her pregnancy at the third time point. Thus it appeared that she was trying to negotiate a transition in her own life, involving the need to individuate while recognising that her parents needed support and that she needed them. Consequently, while being closer together had clear benefits for this family, it also presented new challenges for their relationships because it disrupted normative patterns of relating and transitions such as that of non-interference described by Rena (c.f. chapter 6) and Rachel's struggle to individuate and develop a new family, while recognising her parents increasing needs.

In both the Perrin and Morris family as described previously (Chapter 7, p.159-60), closeness between grandparents with bvFTD and their grandchildren also continued. Similarly, although relationships between generations were not always positive, this also occurred in the Burton and Lewin families. Family members sought to support interaction and reinforce

the value of relationships between grandparents and grandchildren, thus maintaining close bonds (c.f. chapter 8, p.261-2).

An entrenched we

Five families experienced ruptures in their relationships with wider family members, leading to an entrenchment of positions which in some cases, resulted in losing we (Burton, Hugh, Stuart, Lewin and Horton). In all five of these families, these ruptures were influenced by previous difficulties in relationships, a lack of understanding of each other's experiences and a lack of congruence in awareness and understanding.

Difficult prior relationships between family members were experienced by all five families to some degree (c.f. chapter 6). Relationships that were characterised by degrees of disconnectedness, lack of closeness, poor communication and difficulty in addressing conflict or challenges such as those described by Pamela and Jonathan Hugh and Carole Stuart appeared to be ill-equipped to manage the challenges brought about by bvFTD. The need to have increasing contact and offer increased levels of support for parents appeared to intensify existing relational difficulties. For example as indicated previously, Carole Stuart described a history of relationship difficulties with both of her parents, which she had tried to address following the birth of her daughter. Furthermore, despite her anxieties about caring for her parents, Carole had increased her contact in order to support them following her father's diagnosis. However as can be seen below (table 9.16) further conflict seemed to result in the need to revert to keeping an emotional distance as was evident earlier in her adult life:

Table 9.16: Difficult prior relationships

Carole	*[…] I moved out when I was 19, so I left home when I was 19 and came to live round this area. So that's quite a few years ago now. […] So my visits, because we're so busy and stuff were quite like once a month, once every two months. […] I would say ... that a lot of the time I have to be the adult in the relationship that's the way I always felt. I felt like I had to grow up quite quickly....[…]*
Jenny	*You were saying that you've felt you've had to be the adult.*
Carole	*Yeah always in that way. I think my brother's always been very selfish.*

Jenny	*Right.*
Carole	*And so because they didn't have much money my brother screamed and shouted for what he wanted and made mum feel very guilty and he always got what he wanted so I always was the one that said, "No I'll have the board game or something," whereas he wanted a mountain bike or a brand new computer. So in that way I felt a lot of resentment to my parents up until I had counselling for it. So my relationship was quite strained with them but we seem to be okay now but I do have this real panic inside of me that I'm going to be the one looking after them. [T1]*
Carole	*We've had a bit of…well we were quite close up until Christmas time but my brother's split up with his fiancée and moved out and he's had quite a lot of drama and stuff which I think he's taking advantage of them quite a lot financially.*
Jenny	*Okay.*
Carole	*And one of the reasons why they wanted to go on Christmas day really was because they'd had an upset with my brother's ex but she hadn't told me that on Christmas day which would have been like more understandable. She was supposed to be staying and then they made lies up to go. And I didn't appreciate that because I had to clean the house…because mum's spotless, I'd cleaned the house and working full time and trying to do everything it was a lot, I was absolutely exhausted […] that really annoyed me at Christmas, really annoyed me that I'd put so much effort into it and she knows how busy I am and she couldn't tell me the truth. And we did have words about it but not quite out in the open because she just gets too upset about things. So yeah. So it's knocked things about because we were…because I was taking her to the hospital and stuff before Christmas, we were getting quite a lot closer really but I've sort of stepped back again.*
Jenny	*Yeah.*
Carole	*I keep me guard and the barriers have come up […] [T3]*

Consequently, entrenched patterns of relating within this family were further accentuated by the challenges brought by bvFTD. In the absence of coping processes such as open communication, this resulted in a negative impact upon relationships between generations involving actual and emotional distance and disconnection.

In the context of difficulties in being able to appreciate or understand each other's perspectives, disconnectedness and conflict occurred in relationships. For example as described previously (chapter 8, p.210-2) Mollie and Anthony Burton experienced difficulties in their relationship with Mollie's daughter

Diane. It seems possible that they did not appreciate that it might be difficult for her to understand the changes Anthony was experiencing and what this might mean for him and for Mollie. Similarly, although they described being closer to Jane Burton, it seemed that they struggled to appreciate that she might be finding the changes in her father difficult:

Mollie *Jane's quite good, but I don't know if we've upset Jane, because she usually comes round, but Anthony comes out with things now, you see, that and Jane's one to get easily up... You said something to her one day and she was nearly in tears and I don't know what it was. I can't remember what you said to her. She's got to learn to take things, because something you said to her, was it... What was it, about Joe? 'He should get out and get a job.', or I don't know what it was you said. Whatever it is, I see the tears and I thought 'Well I'm not saying anything. She's got to learn that they just come out.'*

Anthony *But she molly coddles him too much. I mean, he's eighteen now […].*

Mollie *I don't know if she... She's used to sitting there and Dad 'Yes, nice, nicey-nicey.', but now he doesn't. [T3]*

In the quote above Mollie seemed to assume that her lack of contact was because of Anthony's behaviour and her lack of understanding. Jane indicated in her first interview that she was aware that he would say inappropriate things:

Jenny *And are there other things that you've noticed when you're out together that he does that perhaps he wouldn't have done before?*

Jane *I think he speaks his mind a lot more now, whereas before he was a fairly placid quiet man and he would keep his thoughts to himself, whereas now if he sees somebody or something that he doesn't agree with he'll just turn round and say so and he doesn't really care who overhears him or anything, whereas before he would be very conscious about*

people overhearing him say something like that. So he wouldn't speak his mind so much before. Well never actually [T1]

Thus they appeared to struggle to consider her perspective such as how the changes in her father might impact upon her emotionally. Therefore they did not seem to recognise or address her emotional needs. In the context of these difficulties, it seemed that Diane and Mollie experienced conflict and a degree of emotional distance in their relationship. Similarly Jane also seemed to experience an increasing emotional distance from them. As discussed previously in chapter 8 (p.238-9), it also seemed that Phil Horton may have had difficulty in appreciating the impact of his wife's behaviour on his daughter. His daughter had made a decision not to allow her children to be exposed to her mother, even though he appeared to want that contact for his wife:

Jenny *Do the grandchildren come?*

Phil *No.*

Jenny *No. Okay.*

Phil *I think my daughter's frightened for them to see their Nan in the current state. She wants them to remember her when she was who she was.*

Jenny *Yeah.*

Phil *I've suggested a few times that it might be a good thing for her mum to see the grandchildren but my daughter's frightened that if she comes and they don't…and she turns aggressive it might have a negative impact on the children.[T2]*

Thus it appeared that for some families, this difficulty in appreciating each other's perspectives could lead to further disconnectedness between generations.

Finally lowered levels of awareness and understanding could also lead to difficulties within relationships. As has previously been described (chapter 7, p.147-9) lowered levels of awareness within families, where this occurred

in the context of limited connectedness and proximity caused some family members to be positioned as the problem (chapter 8, p.210-2). This occurred in the Lewin, Burton and Hugh families. All three families described the breakdown in some relationships as a consequence of a lack of congruence in their understanding. For example the Lewin family suggested that relationships with some of Ray's sisters had broken down. Similarly, Pamela described the loss of her relationship with Stan, her brother. Indeed Pamela described her sadness at the loss of this relationship:

Pamela *And I'm just amazed at how it's affected out family. You can't believe that you know […] we're not even talking to each other.*

Jenny *And is that different from before?*

Pamela *Yeah. Initially, when she was first ill we used to talk frequently, […] he was the one who said "There's definitely something wrong." So initially, we were talking. But to now be at the stage where we won't even speak to each other unless there's something specific to say. For instance, before Jonathan went in hospital, the carers had said "Has your mother got another light switch in her kitchen? Because it's really dark?". […] so I actually texted Stan and said "Can you sort the lights out? Jonathan's going in hospital tomorrow. We can't do it." So at that point he said "Ooh, what's the matter with him?". So I told him. So Stan didn't even text me or anything to say 'Well, how is he?'. […] He hasn't phoned to see how Jonathan is. And it's Sebastian's birthday today, he hasn't sent him a card. […] So that is how it is now. And that is really dreadful. [T2]*

It therefore appeared that these families may also have experienced a sense in which they were losing 'we'. As in the context of a lack of cohesion, open communication and conflict management within these families, difficulties such as those described above did not appear to be addressed. Indeed coming closer together caused further challenges and damage to relationships.

9.6 Chapter Summary

In this chapter I have considered the outcomes for family relationships when a member of the family has bvFTD. Relational outcomes were evident for families, close family relationships and individuals. These ranged on a continuum from '**a changing we/ I to an entrenched we/ I'**.

> A changing we --- an entrenched we: relational outcomes for close family members

Close family members experienced considerable changes to their relationships as a consequence of the interplay between the effects of bvFTD and their prior relationship. Consequently, a range of outcomes were evident, reflecting the diverse nature of relationships within these seven families. While acknowledging the changes and their impact, two couples were able to accept and adapt to the changes. Collaboration between the person with bvFTD and their partner characterised their coping, with one of these couples involving wider family in collective strategies designed to support the continued involvement of the person with bvFTD in everyday family life. In this context couples sought ways to maintain their strong bonds.

A further two close family members (one partner and one couple) described the changes and acknowledged the loss of the relationship as it was. For one partner this occurred because the person with bvFTD no longer recognised them and had been placed in long term care. The fundamental nature of the changes resulted in a shift for Phil Horton towards seeking a new relationship while remaining connected to Penny. Over the duration of their involvement in the research, Alistair and Kate Perrin gradually recognised that their coping process of 'fighting it' was not successful in keeping changes at bay which caused distress at the loss of core aspects of their togetherness. While losing 'we', the couple remained connected, although the nature of this connectedness had fundamentally altered. Kate openly acknowledged the shift in their relationship from husband wife, to parent child.

Two further close family members described a loss of the person with bvFTD as they were and therefore experienced a loss of togetherness (one adult daughter and her husband and father and one couple). In the absence of a

shared understanding of the changes, poor communication and difficulties in addressing the emotional impact of such changes these family members experienced grief, frustration and anger at the changes. Furthermore, they seemed unable to tolerate the changes in the person with bvFTD and positioned them as the problem. Coping in this way appeared to cause family members including the person with bvFTD to work separately from each other in order to address their individual needs. However the adult daughter and her partner seemed able to seek ways of strengthening their relationship as a consequence of the challenges they experienced.

Pamela Hugh and her partner experienced a relationship characterised by distance and disconnectedness with her mother Elizabeth, in which distance from each other was valued. BvFTD disrupted these carefully maintained boundaries as this family needed to come closer together to cope with the changes. In the context of these relationship difficulties and a lack of understanding of bvFTD Elizabeth was positioned as the problem. Consequently, the nature of the contact required to manage the changes in Elizabeth caused further damage to their relationship. Pamela and Jonathan experienced significant challenges in addressing their own relational needs and in finding a balance in their caregiving. Ultimately they appeared to have become resigned to their role and expressed the view that they would only be free of this when Elizabeth died.

A changing I --- an entrenched I: relational outcomes for partners, adult daughters and their partners

Changes to we incurred challenges to self for these close family members. BvFTD seemed to require family members to have a ‘foot in both camps’. That is to find a balance in supporting the person with dementia while addressing their own relational and individual needs. Adaptation to meeting their own needs was a gradual process, brought about by pivotal changes such as the need for care, the loss of valued relational characteristics and deteriorating personal wellbeing. Consequently, while remaining attached, some of the partners and adult daughters and their husbands gradually sought to invest in other relationships in order to meet their needs. This was

not without challenges, as for example, confiding in adult children may be at odds with their wish to protect them from the consequences of bvFTD. Similarly it may be that relationships with wider family are such that coming closer together was not possible or support was not available.

Other partners and adult daughters seemed to be stuck and unable to move to a new self. Difficulties with prior relationships, ruptures in relationships with the person with bvFTD and a lack of shared understanding appeared to cause these close family members to feel helpless to influence change and to feel alone. Consequently it appeared that even when recognising changes to their own wellbeing, they were unable to implement or sustain measures designed to care for themselves.

A changing we --- an entrenched we: relational outcomes for wider family members

In the context of a prior relationship involving connectedness, open communication, successful resolution of conflict and cohesion, two families sought to work together with wider family members to address the changes and facilitate the continued involvement of the person with bvFTD in their lives. Family members moved closer together and engaged in mutual exchange of support to address emotional and practical day to day needs. Furthermore it was possible for relationships to continue to thrive albeit in a different form, such as with grandchildren. However, while closeness appeared beneficial to these families, it was not without consequences, including exposure to loss and sadness associated with the changes; fears for the future; fears for the wellbeing of the person with bvFTD and their partner and disruption to normative developmental transitions.

For five of the families, the onset of bvFTD resulted in increased closeness. However in the context of difficult prior relationships involving poor communication, a lack of ability to take each other's perspective and a lack of cohesion, these families experienced ruptures to their relationships with wider family members. This appeared to lead to an entrenchment of pre-existing relational positions involving emotional and practical distance.

Furthermore, in some families a loss of relationships and/ or increased conflict appeared to occur.

<table>
<tr><td colspan="5">Superordinate Themes and Subthemes Overview</td></tr>
<tr><td>Superordinate theme 1:</td><td colspan="2">We/ I before bvFTD</td><td>Cohesive and connected</td><td>--------
Disconnected and distant</td></tr>
<tr><td>Superordinate theme 2: Challenges experienced by we/ I</td><td>Influencing Elements</td><td colspan="3">Superordinate theme 3:
Assimilating, adjusting, reconstructing -------- Resisting, denying, being stuck</td></tr>
<tr><td>Awareness and understanding of the changes</td><td>Emotional and physical proximity,
It’s really subtle and difficult for others to see,
Readiness to see and hear the changes,
Prior relationship,
Availability of knowledgeable and supportive professionals,
Understanding of bvFTD.</td><td colspan="3">Accepting and Assimilating
It’s dementia, we have to find a way through this -------- Resisting and Blaming
Resisting knowing,
They are the problem,
You’re the problem, you don’t work with us or help us,
Distancing.</td></tr>
<tr><td rowspan="2">Managing everyday life</td><td rowspan="2">Availability of knowledgeable and supportive professionals,
Accepting – resisting—rejecting,
Awareness – Unawareness,
It’s really subtle and difficult for others to see,
Past experiences of similar difficulties,
Peer support,
Prior relationship.</td><td>Enabling and Facilitating</td><td>Distancing, Managing and Controlling</td><td>Avoiding and Reacting</td></tr>
<tr><td colspan="3">Underpinned by Collaboration, Adaptation, Communication, Addressing Conflict and Cohesion</td></tr>
<tr><td rowspan="2">We’re not the same anymore/ I’m not the same anymore</td><td rowspan="2">Awareness – Unawareness,
It’s really subtle and difficult for others to see,
Living together by choice,
Prior relationship.</td><td>Accepting and Adapting
Accepting the changes and finding new ways of being together</td><td>Fighting
Resisting the changes, we’re going to fight this together</td><td>Distancing and being stuck
Achieving Distance,
Being stuck.</td></tr>
<tr><td colspan="3">Accepting the need for a changing I
Grieving for a changing you and a changing we
Acknowledging the need for a changing I
Accepting the need for a changing I</td></tr>
</table>

Being me in the context of bvFTD	*In step or out of step in our awareness of changes,* *Family coping processes,* *I trust my family's' ways of supporting me,* *Sense of self,* *The impact of bvFTD on social and cognitive functioning,* *An important person in our lives --- he was just there really,* *Understanding their emotional world.*	**Maintaining Self:** ○ *I'm still me, still active and engaged with life* ○ *I'm still me there's nothing wrong* ○ *I'm still me, resisting negative perceptions* **Maintaining Wellbeing:** ○ *Supporting safety and security (a collaborative process)* ○ *Holding them (family members)* **To** ○ *Resisting and restricting (person with bvFTD)* ○ *Controlling, positioning and distancing (family members)*
Superordinate theme 4:	Relational Outcomes	**An entrenched we / I** -------- **A changing we / I**
Relational outcomes for close family members including the person with bvFTD (along the continuum)		• A changing we, stronger in a different way • Losing we, but still connected • Losing you so losing we, together but separate • There is no we, just getting through it
Relational outcomes for partners, adult daughters and their partners: the need for a changing I		Becoming a new I ----- An entrenched I
Relational outcomes for wider family members (along the continuum)		• Closer together • Conflicted • Losing 'we'

Chapter 10 Discussion

10.1 Introduction

In this final chapter of the thesis, I consider the findings of the research study in the context of existing literature. Initially, I compare the results of this study with those of the systematic synthesis described in the literature review. Following this, those results that are consistent with existing research are explored. I then discuss the findings that appear to be unique to this study. After these two sections, I consider the potential implications of the findings for interventions and practice. I then summarise my own influence on the research, following which, I discuss the limitations of the study and the implications of the findings for future research. Finally, I conclude by considering the extent to which the research questions posed at the outset of the study have been addressed.

10.2 Links between the current study and the results of the systematic synthesis exploring family relationships and dementia.

In undertaking the current study, I sought to address some of the main limitations of research highlighted in the systematic synthesis described earlier. This included seeking the involvement of the person with bvFTD in the study; recruiting families with a range of relationships; focusing on a less common form of dementia and taking a longitudinal approach. In addition, where possible I sought to recruit wider family members to the research, in order to gain a family perspective on living with bvFTD. Further studies are required to consider the potential impact of bvFTD on diverse family constellations including those influenced by varied ethnicities or sexual orientation.

The results of the systematic synthesis identified four superordinate themes: **a shared history, negotiating the impact of dementia upon the relationship, openness and awareness** and finally, **shifting sands.**

A shared history contained two subthemes which appeared to represent opposite poles on a continuum; *A good life together* through to *disconnected.* This superordinate theme has strong parallels with the superordinate theme

Cohesive and connected ---- Disconnected and distant in the current study. While the synthesis largely reflected the relational characteristics associated with couples or adult daughters and their mothers, family relationships in the current study seem to reveal similar features. That is, the strength of the emotional bond, commitment, communication, the ability to resolve conflict and to share roles provide the bedrock upon which dementia is addressed within a family as well as a dyadic context.

Furthermore, as in the systematic synthesis, families made links between the qualities of their prior relationship and their experience of their current relationship and their motivations for supporting the person with bvFTD.

The three superordinate themes of *Negotiating the impact of dementia upon the relationship, Openness and Awareness* and *Shifting Sands* similarly have strong parallels with two of the superordinate themes **Challenges experienced by we/ I** and **Assimilating, adjusting and reconstructing --- Resisting, denying, being stuck** described in the current study. The seven families experienced challenges associated with becoming aware and understanding bvFTD, managing everyday life, managing the impact of dementia upon close relationships and retaining a sense of self in the face of dementia. As with the synthesis, families' responses and coping processes associated with these challenges appeared to range on a continuum from seeing the dementia as a challenge to be met collaboratively through to experiencing ruptures in relationships as family members struggled to maintain or support connectedness in the face of dementia.

Consistent with the synthesis, some families described sharing their understanding, supporting each other emotionally and adjusting and adapting. This occurred in spite of the altered levels of awareness of the person with bvFTD, as family members sought ways to involve and include the person in everyday family life. Families at the opposite end of the continuum appeared to experience challenges with awareness and understanding. As a consequence they also positioned the person with bvFTD as the problem and indeed other family members who were out of

step in their awareness. Strategies described in the synthesis involving minimising and working apart also featured in the current study, with family members appearing to distance themselves from each other and/ or experience increased conflict in relationships.

The current study however extends and provides more depth concerning the specific experience of the impact of bvFTD. As described in the synthesis, it is the psychosocial impact brought about by bvFTD that appears to be significant. There is considerable evidence of individual variability in the experience of dementia generally (Eschweiller et al. 2010) and there is recognition that symptoms commonly associated with bvFTD such as impairments in social cognition and executive function also occur in other forms of dementia. Nevertheless, it appears that for the participating families, changes to social cognition and executive function had a profound and early impact upon the person's ability to engage in everyday family life, even before diagnosis, thus necessitating fundamentally altered ways of relating. This appears to be different from those living with Alzheimer's disease and other more common forms of dementia included in the synthesis, where evidence of continued mutuality in relationships early in the experience was possible.

The final superordinate theme in the current study, **A changing we / I --- An entrenched we / I,** considered the relational outcomes associated with the experience of bvFTD for these seven families. BvFTD impacted upon the relationships of whole families, individual family members as well as on close family relationships, reflecting the diverse nature of relationships within the participating families. As indicated previously, the use of the term outcomes was not to imply an end point had been reached, rather it represented the perspectives of families about their relationships at that point in time. Families and individuals within families experienced varying degrees of changes to relationships on a continuum reflecting the extent to which they were able to adapt and adjust to the changes brought about by bvFTD.

I did not explore relational outcomes in the synthesis. Having completed this study, it is evident that considering relational outcomes in the original synthesis would have been a valuable addition to the process. However, the majority of the studies included in the synthesis used a cross-sectional design which would have rendered it difficult to identify outcomes, which meant it did not emerge as a theme. Nevertheless, a small number of the articles did use a longitudinal design and reflected on changes to relationships. For example Hellström et al (2007) identified that couples engaged in a process which ultimately involved either becoming 'a new we', 'becoming an I' or engaging in a new beginning. These outcomes have parallels with the findings of the current study in reflecting changes within relationships as well as for individuals. Furthermore, consistent with the findings of the current study, Roach et al. (2014a) also identified relational outcomes in some of the family storylines, involving for example ruptures or distancing in relationships with wider family.

10.3 How the findings relate to existing literature

The findings of this current study are related to existing research in regard to:

- The interplay between past and current relationship quality and its impact on the experience for family members
- The ability of people with bvFTD to contribute to research
- The awareness of the person living with bvFTD
- Assimilation and understanding of changes for the whole family
- Coping styles
- Identity, selfhood and wellbeing for people living with bvFTD
- The specific experience of partners and adult children concerning the impact of bvFTD on their relationship with the person with dementia and its effect on their own identity
- Scaffolding strategies used by families to support wellbeing and functioning in people living with bvFTD.

The interplay between past and current relationship quality and its impact on the experience for family members

In my research, the experiences of these seven families provided a powerful representation of the interplay between past and current relationship quality and the influence of this on the wellbeing of participants. In some families, a previously positive relationship appeared to enable the family to engage its resources to find ways of maintaining the quality of the current relationship albeit in a changed form. Conversely, in the context of a previously distant and disconnected relationship, bvFTD brought strain and conflict to current relationships. These findings correspond with existing research that emphasises the link between past and current relationship quality and the implications of this, both for the wellbeing of the person primarily involved in caregiving and the person with dementia (Quinn et al. 2009; Fauth et al. 2012; Morris et al. 1988). These findings are also supported by the results of the systematic synthesis reported earlier (La Fontaine and Oyebode 2014).

However, as also found in these studies, it cannot be assumed that a previously positive prior relationship will always lead to current relationship quality or wellbeing of family members. The findings of the current study demonstrate that bvFTD brings particular and early challenges for family relationships because of its effect on features of social cognition and executive functioning. While a positive prior relationship may support family adaptation to bvFTD, this does not necessarily mediate the experience of grief and loss at the considerable changes in the relationship. In some family members, the nature of the changes caused them to evaluate the relationship as having fundamentally altered in a negative way which had implications for the emotional and physical wellbeing of partners and adult children. These findings indicate that bvFTD has a particular influence on relationship quality and wellbeing.

The ability of people with bvFTD to contribute to research

Five people living with bvFTD participated in this research. In Chapter 2, I reviewed the limited research which exists concerning the experience of people living with bvFTD. Griffin et al. (2015) and Avineri (2013) have both

challenged the dominant narrative that people living with bvFTD cannot contribute to research due to lack of awareness and insight. This current study confirms these authors' assertion that people living with bvFTD can indeed articulate their experience. All five people were able to give insightful accounts of their day-to-day life with bvFTD. While awareness was variable, this did not conform to the literature which appears to suggest that awareness and insight is absent. Rather, as Avineri (2013) suggests, this would be more appropriately viewed as being on a continuum of unawareness to awareness.

Avineri (2013) and Griffin (2015) also commented upon the context in which research should take place and the nature of the modification to research design that needs to occur to ensure participation. The family context of the research appeared to be significant. Four of the five people living with bvFTD chose to be interviewed together with their close family member. Where close family members were cognisant of and responsive to their needs during the interview process, this appeared to support their contribution.

The awareness of the person living with bvFTD

Parallels between research considering awareness in people with Alzheimer's disease and the current study were apparent. Clare (2002; et al. 2005) considered the awareness of people living with Alzheimer's disease, describing participants as being on a continuum of self-maintaining to self-adjusting in their coping styles, reflecting varying degrees of awareness of the changes they were experiencing and their coping responses in light of this awareness.

In the current study, the participants with bvFTD also demonstrated variable levels of awareness and associated coping styles. Two appeared to be closer to a self-adjusting coping style, although it appeared over time that self-maintaining strategies were also used. Conversely, one appeared to hold to a self-maintaining coping style throughout the research, whereas two others appeared to fluctuate over the duration of the research in regards to their position on this continuum. One person in particular appeared to adopt a largely self-maintaining style, due to his concerns about stigma and the

perspectives of others. However over time, he seemed to become more at ease with his diagnosis and was able to begin to tell others and accept support from others, suggesting features of self-adjustment.

Therefore consistent with the findings of Clare et al. (2005), it appears that people with bvFTD in this study sought ways to cope with the impact of bvFTD, with some having greater levels of awareness than others. Clare et al (2005) also focus on the experience over time which is consistent with these findings, in that the people with bvFTD in this study seemed to experience some shifts in coping styles which may be influenced by a number of factors including adaptation and assimilation of the diagnosis.

However, while degrees of awareness were apparent, participants had lesser awareness of the nature and extent of the changes and the impact of them, than their family members. Furthermore, in contrast to the findings of Ablitt et al. (2010), people with bvFTD in this study also appeared to have less emotional awareness of the impact of the changes on their family members. While some appeared to recognise the changes at a cognitive level, 'in the moment' emotional recognition seemed to be significantly affected. In this context, some participants appeared to have meta-awareness in that they recognised that they had less awareness than their family members. Consequently they appeared to attempt to integrate other's understandings of the changes into their narrative and were open to strategies which, when supported by family members, sought to address difficulties that their behaviour might cause. However others did not appear to have this understanding which resulted in relational difficulties. This finding is consistent with Avineri's (2013) view that the relational context may be an important factor influencing awareness in people with bvFTD. Furthermore, it attests to the relational context of adjustment and assimilation of dementia (Snow et al. 2015). With this in mind, I now turn to the awareness and understanding of changes for the whole family.

Awareness and understanding of changes for the whole family

Family members in this study appeared to have varying degrees of awareness and understanding, influenced by a range of factors including

emotional and physical proximity to the person with bvFTD and willingness to hear and see the changes. Close family members were often the first to notice changes, while those who were in contact less frequently appeared to remain unaware for significantly longer. Consistent with recent research on developing awareness and help seeking, it seems that in these families, help seeking occurred as a consequence of active reflection and/or in response to pivotal moments (Perry-Young et al. 2016) and was primarily initiated by close family members. Nevertheless, in three of the families, the person with bvFTD seemed to acknowledge that seeking help was necessary, thus it appeared to be a negotiated process (Chrisp et al. 2013).

However, the development of dementia at a younger age is associated with longer time to diagnosis and difficulties in detection and misdiagnoses before a diagnosis is reached, particularly in the context of less common forms of dementia such as bvFTD (van Vliet et al. 2011). Consistent with this, three of the families described experiencing long periods of time and difficulties with professionals before receiving a diagnosis. Of the three families that had shorter time periods from initial contact to diagnosis, their experience was enhanced by contact with knowledgeable GP's and subsequently with a newly formed and skilled team. Experience of knowledgeable and informed professionals appeared to enhance opportunities to develop awareness and understanding (Kelly and Innes 2016). In some families that did not have access to such support, this appeared to be a contributory factor hampering awareness and understanding.

Developing awareness and understanding following diagnosis was an important factor influencing family adjustment and the development of strategies to address the impact of bvFTD on their lives. Cheston (2013) describes the 'assimilation of problematic voices' model, initially developed by Stiles (2001) as a meaningful way of understanding the process through which a person can be supported to assimilate the diagnosis of dementia and live well. Cheston (2013) proposes that seven levels are associated with the process, moving from warding off through understanding and gaining perspective and ultimately, resourcefulness, problem solution and mastery. Recently, this process has been applied to the experience of couples (Snow

et al. 2016), demonstrating that strategies used by couples could support or alternatively prevent assimilation occurring. These findings are consistent with the current study, as it appeared that families varied considerably in their ability to communicate, empathise and openly acknowledge the changes thus moving towards assimilation. Furthermore, these authors described assimilation as an oscillating, dynamic and fluid process (Snow et al. 2016), that also has parallels with the experiences of the families in this study. In particular this was evident in changes in awareness and understanding over time within families. For example, some wider family members took considerably longer to move towards assimilation than close family members, or were stuck at a particular stage, such as warding off. This resulted in conflict or distancing between family members in the context of previously poor relationships.

Coping styles

Existing research has considered the coping styles of family caregivers. These have commonly been categorised as emotion-focused or problem-focused (Snyder et al. 2015). Within the emotion-focused category, it is suggested that there are dysfunctional strategies (such as blaming self) or functional strategies (such as forgiveness and spirituality). Recent literature has also considered the coping styles of spouse and adult child caregivers in the context of bvFTD, as described in the literature review (Roche et al. 2015; Wong and Wallhagen 2014). The current study also evidenced these different forms of coping in close family members. Although existing research tends to suggest family caregivers use one main coping style (Snyder et al. 2015) in the current study, there was evidence that family members engaged a combination of these coping styles, across a range of different situations although one form of coping may be more dominant. Similarly, there was also evidence of flexibility over time in coping styles.

Nevertheless, existing research that considers coping has limitations. For example, Snyder et al. (2015) acknowledge that they did not control for or consider the breadth of factors that may influence coping, such as appraisal which is thought to influence coping styles (Lo Sterzo and Ortega 2015).

While the current study is a small qualitative study and cannot be generalised, it appears that what is important is what works for the person and their family at that time and in that situation, rather than a focus on one form of coping as being more effective than another. Furthermore, as identified by Lazarus and Folkman (1984) a range of factors may influence coping processes. In this study these included the past relationship and family functioning.

Identity, selfhood and wellbeing for people living with bvFTD

A significant body of literature has considered identity, selfhood and wellbeing in the context of dementia (c.f. Kitwood 1997; Sabat 2001). However the perspectives of people living with bvFTD have largely been absent from this literature. Instead, the dominant discourse around bvFTD has focused upon underlying pathology, symptoms and associations between behaviour and caregiver outcomes. A risk of this focus is that the identity and personhood of the person with bvFTD is marginalised and as Kitwood (1997) and Sabat (2014) have identified in relation to the experience of dementia more broadly, their experience is reduced to a set of symptoms to be charted and monitored. In applying Stern's Critical Personalism theory, Sabat (2014) challenges us to recognise that people with dementia have a host of *"intact psychological, emotional and cognitive abilities that would be unnoticed if we were to restrict our understanding of such people to their performance on standard neuropsychological tests"* (35).

The current study adds depth to this small body of evidence concerning the personal experience of bvFTD and the challenges faced by people with bvFTD in living well. Active efforts to maintain selfhood were apparent in all five participants and this study details the range of ways in which the five participants sought to maintain their selfhood and identity. These are consistent with Sabat's discussion of Critical Personalism (2014) and included continuing to perceive themselves as embodying the multiple roles they have held through their lives. Furthermore, there was evidence of self-maintenance, involving resisting the way in which they were perceived by others (autotelic goals: Sabat 2014) and although less commonly and in

restricted ways, through reciprocity (heterotelic goals: Sabat 2014). Further research is needed, but the current study adds further support to the challenge made originally by Kitwood (1997) for us to see people with dementia as whole persons.

The current study also highlights the importance of the relational context in which personhood was supported or denied. Consistent with the work of Sabat (2001) and Kitwood (1997) and more recent literature (Le Galés et al. 2016; Sabat 2010; Hydén 2014) selfhood and identity was supported within a relational context. Family members supported the person in regard to their emotional wellbeing such that in one case, the person with dementia felt able to tell others about his diagnosis (Weaks et al. 2015). Similarly some family members sought to minimise the threats to wellbeing that caused the person with bvFTD to feel of insecure and panicky. Furthermore, people with bvFTD acted in collaboration with their family in order to achieve activities associated with everyday life.

> The specific experience of partners and adult children concerning the impact of bvFTD on their relationship with the person with dementia and its effect on their own identity

As described in the literature review, existing research highlights the experience of partners in particular, having an increasing need to take responsibility, including taking on roles that would previously have been carried out by the person with dementia (Pozzebon et al. 2016; Wadham et al. 2016; Lin et al. 2012). Similarly, these authors emphasise the nature of the changes in the relationship and therefore the losses that partners have to contend with. The results of the current study share much in common with these findings, demonstrating that the partners experienced significant challenges associated with the nature of the changes to their relationships. Similarly, the findings of the current study concerning the relationship two adult daughters had with their parent with bvFTD are consistent with existing research (Ward-Griffin et al. 2007; Kjällman-Alm et al. 2013).

However, a limitation of much of the literature in this area is that it combines the experiences of bvFTD with other forms of dementia. As indicated earlier,

the current study appears to suggest that a specific focus on bvFTD is warranted. Close family members in this study reflected on significant and early changes to core aspects of mutuality involving everyday relational work, such as communication and reciprocity. Additionally, changes in the ability of the person with bvFTD to contribute to the practical activities of everyday life were such that 'taking responsibility' for these activities and for their needs was an early and profound shift in the nature of their interactions. This can be likened to the concept of 'second order change' described in systemic theory (Davey et al. 2012), where "*transformation of the system itself*" occurs as a consequence of bvFTD.

In particular some partners characterised the changes as becoming like 'brother-sister' and ultimately like 'parent child'. It is important not to see this as infantilising (although that may occur) but rather it may reflect the difficulty in conceptualising the complex nature of the changes to the level of cognitive and relational sophistication.

Outcomes for relationships involved partners needing to stay attached while simultaneously finding new ways of meeting their own needs (Hellstrom et al. 2007; Keady and Nolan 2003; Pozzebon et al. 2016; Wadham et al. 2016). This included strengthening existing family relationships or finding new relationships; peer support and psychological support. Similarly adult daughters grappled with staying involved while achieving a distance from the person with bvFTD and also finding ways of meeting their own needs.

Finally, the current study appears to support existing research concerning the value of peer support (Keyes et al. 2016) as a source of reciprocity, learning and shared experience.

> Scaffolding strategies used by families to support wellbeing and functioning in people living with bvFTD.

Research exists concerning the use of neuro-rehabilitation, cognitive rehabilitation and behavioural interventions in other fields (e.g. traumatic brain injury) and has been applied in the context of Alzheimer's disease (Bahar-Fuchs et al. 2013; Padilla 2011; Buchanan et al. 2011; Letts et al. 2011). Similarly, research into interventions in the field of dementia care has

involved working with family members to enhance their ability to support the person with dementia (c.f. Gitlin et al. 2008; 2010a; 2010b). Developing scaffolding techniques, such as breaking activities down into component parts and supporting success in one part before moving to another, is a common feature of interventions of this type. It has recently been recommended that there would be value in transferring these strategies to bvFTD (e.g. Nunnemann et al. 2012; Korte and Rogalski 2013; O'Connor et al. 2013). A small number of studies have explored supporting problem solving skills development with family caregivers of people with bvFTD (e.g. Mioshi et al. 2013b) and most recently, one study has illustrated the value of the tailored activities programme in this context (O'Connor et al. 2016). The current study lends support to the recommendations of these reviews and the study conducted by O'Connor et al (2016), that enabling families to work with the person with bvFTD to engage in activity focused interventions which utilise scaffolding techniques can be effective. Furthermore, it appears to provide important means to support functioning, address quality of life and feelings of mastery.

10.4 The unique contribution of these findings: The reciprocal influence between family relationships and bvFTD

As described in the literature review, few studies have considered the whole family experience of living with dementia and none have applied this to the experience of bvFTD. The current study appears to be unique in achieving this. A number of key findings are evident. Consistent with findings from family systemic approaches to illness and disability (Rolland, 1994; Kissane and Bloch 2002; Walsh 2006), this research shows that there is a reciprocal influence between family relationships and the experience of bvFTD. That is, that the family relationship influenced the way in which bvFTD is understood and managed within the family and in turn the changes associated with bvFTD influenced the relational outcomes on a continuum from a changing we/ I to an entrenched we/ I.

Additionally, the findings illustrate that all family members within the system were affected by and influenced the way in which bvFTD was interpreted, understood and managed. While there appeared to be varying degrees of

impact based on emotional and physical proximity, the responses of wider family members had an impact on close family members and vice versa. These relational exchanges influenced family functioning and relational outcomes for each of the families involved. Wider family were for some close family members an alternative source of strength and closeness. However in other families who were less connected, wider family members were sources of further distress and conflict for close family members. These findings echo those of a number of previous studies exploring the value of family support to primary caregivers of people with dementia (Diest et al. 2014; Trujillo et al 2016; Chesla et al. 1994; Sutter et al. 2014; Tremont et al. 2006; Sherman et al. 2013).

The characteristics of family functioning were fundamental to the way in which bvFTD was addressed within the system and affected the outcomes for all family members both individually and together. These characteristics included the extent to which families were cohesive, able to collaborate, openly communicate, manage conflict, adapt and address changes in boundaries and roles within the system (Rolland et al 1994; Kissane and Bloch 2002; Walsh 2006).

Furthermore, the longitudinal nature of this research illustrated the way in which families and individuals within families adjusted over time. Differences in adaptation were unique to each family, reflecting health beliefs, the stage of the family in the developmental life cycle, prior experiences and responses to adversity (Rolland 1994). When combined with the specific difficulties created by the experience of bvFTD, each family and indeed individual family members underwent changes and were required to confront challenges that were unique to them and their specific way of being as a family.

These findings therefore also align with research concerning the influence of family functioning on the stress process when caregiving for a person with dementia (Mitriani et al. 2006; Tremont et al. 2006). These authors suggest that particular styles of family functioning such as conflict and poor cohesion can contribute to the experience of burden in family caregiving.

A particular strength of the current research is that it has included families with less positive relationships, thus presenting a nuanced portrayal of the family experience of bvFTD. These findings are therefore consistent with existing theoretical understandings of the interplay between illness, disability and family functioning (Rolland 1994; Kissane and Bloch 2002). Rolland (1994) suggests that we need to view the family as the unit of care *"in which a broad range of family forms and biopsychosocial interactions are normative"* (12). This requires that their patterns of relating should not be viewed as functional or dysfunctional. Rather, it is imperative that we recognise that bvFTD brings particular challenges which will impact to a greater or lesser extent depending upon family functioning.

10.5 Implications of the findings for interventions and practice

There are a range of implications for interventions and practice with families living with bvFTD and for individuals within these families. These include:

- Family systems approaches to working with families living with bvFTD
- Specific interventions for those family members in close and/ or intimate relationships with the person with bvFTD
- Interventions to support the person with bvFTD to maintain selfhood, identity and wellbeing
- Developing therapeutic practice in professionals and carers in order that they are able to work with families living with bvFTD
- Information provision for families and individuals within families regarding bvFTD

Family systems approaches to working with families living with bvFTD

Benbow and Sharman (2014) suggest that while literature concerning the application of family therapy to dementia has increased in the past 25 years, there are a number of areas requiring further research in order to support the integration of family therapy as a therapeutic approach in dementia care.

These include the need to identify appropriate techniques to evaluate its effectiveness, how to ensure treatment integrity, making techniques from

family therapy widely available and how to train health and social care staff to work with families (2047). They further suggest that "*there is a need for further research which looks more broadly at changes in the family system, at the relationship between the family and health/ social care and in individual members of the family system" (p.2047)*. The current study, although small scale, provides such evidence concerning the interplay between family relationships and bvFTD.

A number of practice implications can be identified. Firstly, incorporating family systems approaches to working with families affected by bvFTD may be a valuable direction for interventions. The current study points to the need to understand bvFTD within a family centred framework. Within this context, the needs of families and individuals within families should be assessed as a prelude to intervention (Rolland 1994). The current findings point to the uniqueness of each family ranging on a continuum from cohesive and connected to distant and disconnected. Therefore assessment needs to consider the range of factors that will influence the family's response to bvFTD.

Following this, interventions are required that are responsive to the specific needs of families and take account of family patterns of relating and existing beliefs concerning health and illness. Research evidence and theoretical frameworks already exist which support the value of such flexible interventions in the fields of cancer (Kissane and Bloch 2002), illness and disability (Rolland 1994; Walsh 2006). Furthermore, the New York University (NYU) intervention for family caregivers of people with dementia has proven success in delivering family focused interventions in the context of dementia, albeit with a focus on the primary family caregiver (Gaugler et al. 2013; Mittelman et al. 2008; Mittelman et al. 2006).

In particular, the findings of the current study highlight that interventions are needed that reflect the best fit for each family. It is widely acknowledged that interventions which are flexible and responsive to individual differences such as those described by Rolland (1994) and Mittelman (2003) may be more effective than prescriptive interventions (Elvish et al. 2012).

As described above, family focused interventions can also be delivered to individuals within a system. The NYU caregiver programme is typical of such interventions (Benbow and Sharman 2014). The findings of the current study support the need for specific psycho-social interventions which recognise the unique experience of bvFTD for spouse relationships and adult children who are caregiving for the person with bvFTD. These interventions would need to incorporate opportunities as required for them to consider the range of feelings that may be experienced, including the grief and loss associated with the change in the relationship (Large and Slinger 2013). Furthermore, this would usefully support close family members to consider their own needs and self-care strategies, involving for example accessing peer support (Keyes et al. 2016) and strengthening existing relationships (Rolland 1994; Mittelman et al. 2003).

Furthermore, given the nature of the changes over time that this study has identified, support to individuals and families would be most beneficial if it were ongoing and accessible to them as they require it, such as that described by Mittelman et al (2003).

Interventions to support the person with bvFTD to maintain selfhood, identity and wellbeing

A small body of existing research has begun to explore ways in which families can be supported to provide opportunities for the person with bvFTD to maintain selfhood and wellbeing (O'Connor et al. 2016; Mioshi et al. 2013b). The findings of this current study confirm the value of such approaches in enabling the person with bvFTD to engage in activities that were personally meaningful to them and enabled them to continue to be active and engaged in family life. Furthermore, consistent with the findings of Le Galés and Bungener (2016) the person with bvFTD was able to collaborate with family members where this was appropriately supported through scaffolding. A person-centred approach (Kitwood 1997) is of critical importance to such interventions, achieving an individualised assessment and identification of activities that are relevant and meaningful and appropriate to the strengths and challenges the person experiences.

Furthermore these interventions should provide the conceptual framework necessary for the family to adopt an enabling and facilitative approach (Le Galés and Bungener 2016; O'Connor et al. 2016).

Developing therapeutic practice in professionals and carers in order that they are able to work with families living with bvFTD

Benbow and Sharman (2014) identify the need to improve knowledge and understanding of therapeutic practice with families living with dementia. The current study highlights the need for professionals to understand the specific experience of bvFTD and how to support families in this context (Nunemann et al. 2012). In particular, the findings underscore the challenges faced by families and the complexities of their experience. While some found professionals and carers to be knowledgeable and supportive, others appeared to have found professionals and carers to lack understanding.

These findings are consistent with existing literature considering the experience of people living with young onset dementia (Nunnemann et al. 2012; Sansoni et al. 2016). Education and training needs to be available to support knowledge, skills and therapeutic practice, in order that professionals and carers can personalise support for families. This is particularly important as unmet needs appear to have a significant relationship with lower health related quality of life (Bakker et al. 2013).

Information provision for families and individuals within families regarding bvFTD

The findings of this study support the need to provide specialised information concerning bvFTD for families. Information already exists concerning the nature of bvFTD, but this is largely focused on symptom description. In light of the current findings, it would appear that this needs to be extended in the same way that information exchange concerning more common forms of dementia has developed. For example, Barnes et al. (2016) suggest that the provision of information that *"gives meaning to everyday experiences can enable carers to feel better able to give care, enhancing their capacity as well as their sense of achievement and security"* (520). Similarly Pozzebon et al (2016) suggest that spouses frame their experience of dementia within a

relational context, thus information would be most effective if it supported knowledge development within that context. It is within this framework that information needs to address the nature of the changes in order to provide families with a conceptual understanding of bvFTD and how this relates to the person's behaviour on a day-to-day basis.

The current findings also point to the need to consider the way in which information is delivered. The family systems illness model incorporates three time phases of disability; the crisis phase occurring pre-diagnosis through to the period following diagnosis, the chronic phase and the terminal phase (Rolland 1994). Rolland suggests that the way in which professionals deliver information during each of these phases can have a significant impact on family functioning, particularly if this is delivered without understanding the family context or the way in which the family interpret information. This is consistent with the findings of Barnes et al. (2016) who emphasise that people may have very different needs and expectations and without understanding of these, information may be of no value or indeed harmful.

10.6 Reflexivity and reflection on the research and my contribution to the findings

I was well used to working with people living with dementia and their families and had undertaken research with families living with dementia previously when I began this research. I was nevertheless challenged personally, professionally and as a researcher. I had undertaken to engage in personal supervision as a part of this research process. This supervision, alongside the support provided by my supervisors was essential in order for me to consider the challenges I experienced in managing these multiple roles while being party to sometimes unanticipated but nevertheless distressing and difficult experiences. These raised emotionally and sometimes ethically challenging moments for me, involving personal and professional discomfort.

I found it difficult at times to manage the boundaries between practitioner and researcher, recognising that as a practitioner I would have sought to actively address the difficulties experienced by families. I felt constrained by my research role which resulted in my bearing witness to their experiences

without being able to actively work with them. Consequently there were times when I felt helpless to respond appropriately. Sometimes, my response to this internal conflict was the desire to create some emotional distance from the families, which ultimately meant that I could not be 'present in the moment' with them. I felt this sometimes affected the quality of the interviews and my interactions with them.

This experience highlighted the need for ethical practice which cannot necessarily be anticipated and planned for during the research design phase. Such experiences call for person centred approaches which are 'in the moment' and embody ongoing reflexivity, such as that of ethical mindfulness (Warin, 2011). Having recognised the ethical importance of these experiences, the use of supervision enabled me to work with these feelings and manage them so as to limit their impact upon my research practice. In particular, this required that I consider the ramifications for me of emotional engagement with participating families in the context of the research. Hoskins and White (2013) highlight that this is a common challenge for student researchers, particularly in the context of sensitive research topics.

Supervision enabled me to identify strategies to support family participation in the research and address my emotional experience. This involved ensuring that I remained conscious of the family's experiences and as appropriate, offered opportunities to change the way in which we worked together where this was needed (Hellstrom et al. 2007a; Dewing 2007; Sakellariou et al. 2013; Forbat and Henderson, 2005). Furthermore, I explored within supervision, where the boundaries of practitioner and researcher blurred and revisited strategies for supporting participants at the end of the research interview (Sakellariou et al. 2013; Pesonen et al. 2012).

This illustrates how important it was for me to own my feelings and perspectives while conducting this research and consider how these might impact upon the research process, including analysis. Consequently I engaged in personal supervision until the analysis of each of the families had been completed.

I do not claim to know what it is like to live with bvFTD, indeed I have no personal experience of dementia in my family. While I have strived to represent the experiences of the participating families, this needs to be viewed within Riessman's (1993) layers of representation. That is that this thesis represents my interpretation of their experiences as they described them over the duration of the research. My own and their perceptions of their experiences are subject to change over time and are influenced by the wider context in which we each live our lives. Thus these findings cannot be considered to be a single 'truth' but may provide a window of insight into the world of the families who participated.

10.7 The limitations of the findings

There are a number of limitations to this research:

A 'snapshot' of the family experience

This was a longitudinal study considering the perspectives of these families over 3 time points (ranging from 12 to 24 months). While this supports the value of a focus on the interplay between relationships and dementia over time, it is nevertheless still a 'snapshot' of the experience of these families. Further research is needed that explores the reciprocal influence of bvFTD and family relationships over a longer period of time to fully capture the experiences and the possible intervention needs associated with them. Particularly as the experience of bvFTD represents a lengthy and changing course over several years which each family is likely to experience differently.

Achieving theoretical saturation in grounded theory

Only two of the participating families involved an adult daughter as the primary caregiver. Thus the categories developed related to their experience can only be considered provisional as it was not possible to achieve theoretical saturation without returning to the field to recruit new families, which was not possible within the confines of the current study. Similarly, although the categories developed within the experience of families where partners are the main caregivers are stronger, I also believe that returning to

the field would be of value to strengthen these categories and the relationships between them. Thus the grounded theory aspect of this study has not built theory, but nevertheless has highlighted some strong concepts which can be viewed in relation to the experiences of other similar families.

Initial sampling constraints

Given the relative rarity of bvFTD and the anticipated challenges of recruiting family groups to research such as this, I chose not to limit recruitment to a specific time point in the course of the illness. Consequently, there is considerable heterogeneity in some of the characteristics of the seven families that participated. Furthermore, six of the seven families in this study are living with dementia at a younger age. While this reflects prevalence data (Rascovsky et al. 2011), the results are therefore largely specific to the experiences of young onset dementia. While a focus on young onset dementia is a strength of the research given that it is an under-researched area, the experience of bvFTD in older families may be significantly different and requires further study (Baborie et al. 2012).

Similarly, the gender of the five participants with bvFTD and their female partners is likely to have influenced the findings. Thus future studies will need to consider the perspectives of women living with bvFTD and their male partners and/ or adult sons. Similarly, it was not possible to select a sample that included diverse relational experiences, for example same sex couples or families from migrant communities. However, given the sample size it would have been difficult to ascertain the differences that might have been driven by cultural differences or those specific to same sex family relationships.

Rurality

Participants were recruited within a largely rural county with some of the widely acknowledged challenges associated with service provision that rurality brings (Morgan et al. 2011). It is also acknowledged that service receipt for people with young onset dementia and their families is patchy and fraught with difficulties in many areas (Roach and Keady 2008). Thus the service experience of the participating families may be significantly different

from an urban area which has for example, a specialist service for younger people with dementia. Consequently, these findings need to be considered with this in mind.

Research Method

Finally, a limitation of the research may be in my choice of method. Although I sought to capture evidence of 'life as it is lived' through interviews with family members together, this may have been more accessible if I had used participant observation. While I sought to engage aspects of observation during interviews and this proved particularly important in highlighting the nature of the changes experienced it is nevertheless limited. An ethnographic approach based on participant observation and interviews may have been more effective in illuminating the family experience, but this has to be weighed against the invasiveness of such research on the lives of the families, the extent to which observation could be tolerated by the person with bvFTD and the impact of the researcher on the 'naturalistic environment'.

10.8 Implications for future research

In light of the findings, a number of possible areas for further research are identified. Firstly, further study considering the perspectives of adult children as primary supporters of a person with bvFTD is needed. Similarly the perspectives of migrant and minority communities require consideration. While recent studies have explored family functioning and dementia in some countries, (c.f. Diest et al. 2014; Trujillo et al 2016) they cannot necessarily be applied to other communities given differences in cultural context. Furthermore, a specific focus on bvFTD in this context is warranted.

Similarly, the experience of families with different relationship types would be beneficial, considering for example the needs and experiences of families where the person with bvFTD is in a lesbian or gay relationship. Furthermore, it would be beneficial to conduct similar research which reflects different gender relationships, involving female participants living with bvFTD and their male partners and/ or adult sons. Additionally, children and young people within these seven families did not take part. Given the very significant

impact of living with a parent with dementia that has been identified in existing qualitative studies, this would seem to be an area for further research.

Secondly, the findings lend support to the development, piloting and evaluation of a family based assessment and intervention for families living with bvFTD. As Benbow and Sharman (2014) suggest, careful consideration would need to be given to methods of evaluation as well as ways to ensure treatment integrity. A critical factor influencing the practice based relevance of such a study would be to consider how staff working within services can be supported to deliver family focused interventions given the current focus on caregiving. Involving professionals who are already knowledgeable about family focused support, such as Clinical Psychologists and Admiral Nurses (Quinn et al. 2013) may be an important first step to developing such interventions.

Thirdly, an area for future research could be the development and evaluation of meaningful and contextual information for families living with bvFTD. The involvement of families to develop, design and evaluate this information would be a meaningful way forward in ensuring that it is relevant and beneficial. Additionally, given that there is some evidence that the presence of 'expert carers' in psychoeducational courses is meaningful to family members (Barnes et al. 2016), it seems relevant to consider how family members who have experience in this area might be co-educators in delivering such information.

Fourthly, as described earlier in this chapter, research has begun to consider how families can be supported to facilitate meaningful activities with the person with bvFTD that support identity, selfhood and wellbeing. However this is early in its development and existing research has considered people with advanced experience of bvFTD (O'Connor et al. 2016) or is limited to family caregiver interventions (Mioshi et al. 2013b). A further area for study could therefore be to support such activity in families who have recently received a diagnosis.

10.9 Conclusions

In the current study, I sought to understand the inter-generational family experience of bvFTD over time. In particular, I aimed to explore the emotional experience and impact on relationships and the strategies that families used to make sense of and cope with bvFTD. Furthermore, I hoped to identify the practice implications of this research in order to provide the basis on which interventions could be developed. To achieve these objectives, I identified six research questions as follows (Table 10.1):

Table 10.1 Research questions

1. How were family relationships experienced prior to FTD occurring
2. How have families made sense of and understood the changes associated with FTD beginning with the early signs before diagnosis and continuing throughout their involvement in the research
3. What are the implications of this process of sense making for coping with the experience of FTD within a relational context over time? (Considering the verbal, embodied and emotional aspects of coping)
4. How has FTD affected and impacted upon family relationships over time? (considering processes of reciprocity, cohesion, collaboration, communication, conflict, allegiances, roles and responsibilities)
5. What is the reciprocal influence of family relationships and coping processes in the context of FTD?
6. What does this tell us about the factors that facilitate or mediate against living well with FTD and what interventions might be needed in order to support families to live well with FTD?

Using a longitudinal, pluralistic qualitative research design, I employed narrative thematic analysis to explore questions one and four. I employed grounded theory to explore questions two and three. The data arising from these different but complementary approaches were brought together to address question five and to identify implications for practice in line with question six. The study was framed within a constructivist approach, acknowledging that I do not have direct access to the family's experiences and that multiple realities exist.

Within the context of a constructivist approach, I generated “thick and rich description” rather than theory due to the need for further theoretical sampling. I nevertheless believe that I have achieved an in-depth interpretation of the experiences of the seven families who participated, over the duration of the research. The research findings are consistent with theoretical conceptualisations of family functioning (Rolland 1994; Kissane and Bloch 2002). In foregrounding the family as the unit of study, I have illustrated that in these seven families, family relationships form the bedrock upon which the impact of bvFTD is interpreted. Factors such as the extent to which families are cohesive, collaborative and are able to adapt are critical to how they address the unique challenges associated with bvFTD for relationships. In turn, the experience of bvFTD and the way in which it is understood and managed influences the relational outcomes for families and for individuals within families. This is a cyclical process, as the experience of bvFTD is by its very nature progressive and dynamic in its effect. Thus caregiving forms a part of the family experience, but is part of what families do or don’t do, rather than defining them.

Furthermore, in involving people with bvFTD in this research, I have contributed to a small body of evidence which can challenge the dominant approach within research in this area that has risked contributing to a depersonalisation of the person living with the diagnosis. People living with bvFTD are able to contribute their perspectives and experiences. In this context, I have shown that the people within this study were active in interpreting the experience of bvFTD and in seeking to manage its impact on their lives. It is significant but unsurprising, that the achievement of wellbeing and maintenance of identity was dependent upon the extent to which family were able to support, enable and facilitate such activity.

Finally, the findings of this study support a rationale for having a specific focus on bvFTD. The challenges brought by bvFTD for families including the person with dementia appear to be qualitatively different from those experienced with more common conditions such as Alzheimer’s disease. Changes associated with social cognition such as the capacity for empathy and mutuality occurs at an early stage and are complex to understand. When

combined with difficulties with executive function, these impacted upon everyday family life and involved significant losses, changes in relationships, identity and self-concept. Information and interventions are needed which reflect the specific features of bvFTD and assist families to understand these changes within a relational and everyday context. Furthermore, the ongoing and dynamic nature of these changes require that services are flexible in their approach to supporting families; incorporate assessment and understanding of the family relationships and offer interventions that are tailored to their needs. This is likely to mean that services need to be able to offer continuity of support provided within the context of skilled, knowledgeable and therapeutic practice.

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